EXPERIENCES IN HIV CARE IN THE POSTPARTUM PERIOD IN GHANA: THE ROLE OF STIGMA, BIRTHWEIGHT, AND NEWBORN CARE

By

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ABSTRACT

Worldwide, rates of antiretroviral therapy adherence and retention in HIV care (defined henceforth as engagement in HIV care) are generally lower for women in the postpartum period than during pregnancy. To date, studies on women's engagement in HIV care in the postpartum period have not examined the role of low birthweight. In Ghana, caregivers of low birthweight (LBW) infants may be at risk of low engagement because they are a socially vulnerable group. They often are impoverished, experience social stigma for having small babies, and have high depression rates.

This dissertation draws on qualitative interviews with 30 mothers living with HIV (15 with LBW and 15 with normal birthweight infants) in Ghana. It explores how the experiences of caregivers with LBW infants influence their ability to seek HIV treatment and adhere to antiretroviral therapy. Further, it highlights the potential key drivers of retention loss in the postpartum period. All the women in the study were receiving HIV treatment from two tertiary facilities in Accra implementing Option B plus.

Participants' narratives indicate that, in Ghana, social (stigma relating to HIV and baby's size), interpersonal (newborn health concerns) and economic (transportation costs) forces appear to have a greater impact on retention loss in the postpartum period than individual level factors (beliefs and motivations). In addition, they show that mothers with LBW infants are likely to face more challenges with engagement in HIV care than mothers with normal birthweight infants.

Our findings suggest that for sustained engagement of postpartum women in HIV care, a multifaceted approach is needed. Interventions should aim to integrate mother, HIV, and child health services; reduce the financial cost of accessing ART in the

postpartum period, and address stigma. Mothers with LBW infants may need additional support to keep HIV-related clinical appointments and adhere to ART.

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In memory of my beloved host mom, Nancy Anne Tomlinson

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ABBREVIATIONS

ABBREVIATION	NAME
ART	ANTIRETROVIRAL THERAPY
CD4	CLUSTER DIFFERENCE 4
HIV	HUMAN IMMUNODEFICIENCY VIRUS
LBW	LOW BIRTHWEIGHT (<2,500 GRAMS)
LMIC	LOW AND MIDDLE-INCOME COUNTRIES
NBW	NORMAL BIRTHWEIGHT (≥2,500G)
NICU	NEONATAL INTENSIVE CARE UNIT
PMTCT	PREVENT MOTHER-TO-CHILD TRANSMISSION
WHO	WORLD HEALTH ORGANIZATION

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CHAPTER ONE: INTRODUCTION

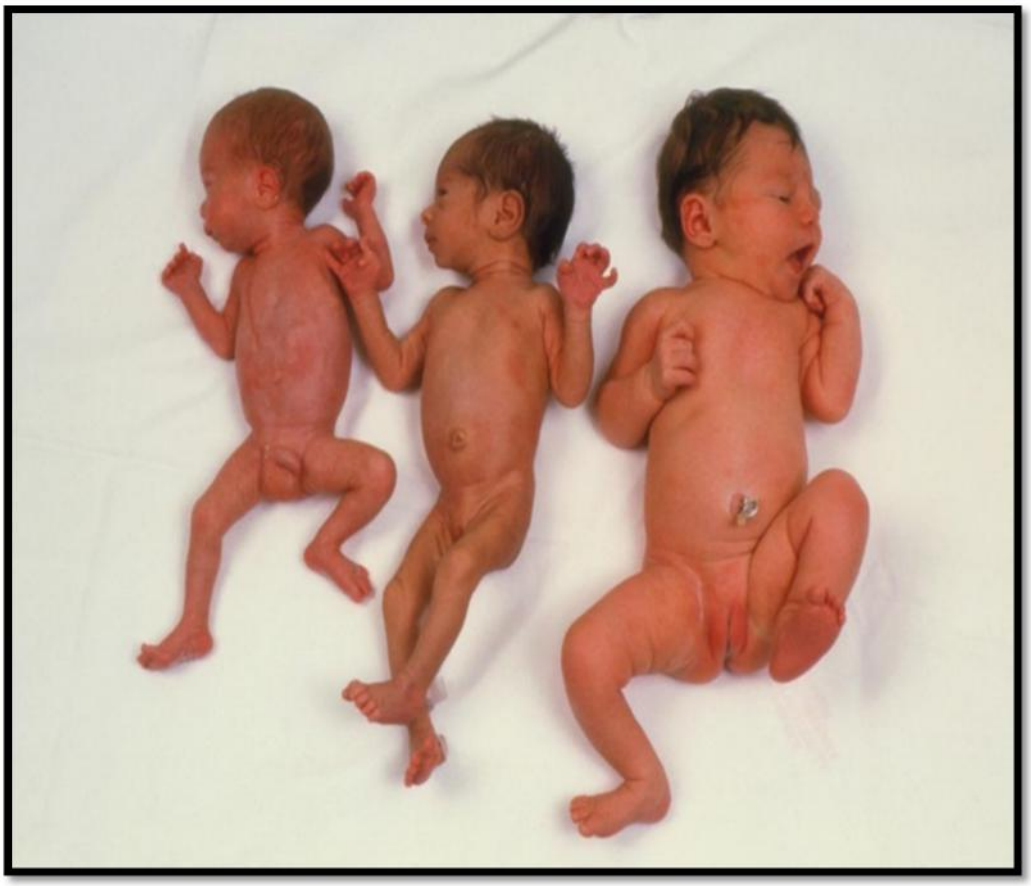

Figure 1: Comparison between two LBW babies and a normal birth weight baby (farthest right).

Source: https://www.sciencephoto.com/media/290824/view

INTRODUCTION

SPECIFIC AIMS

Caring for a LBW (<2500g) infant can have a negative impact on caregivers. Caregivers can experience a sense of guilt, self-blame, alienation, prolonged hospital stay, and high levels of psychological difficulties (including depression and anxiety) [1-7]. In one study in Ghana, about 75% of mothers with LBW, preterm and sick infants reported mild to severe symptoms of postpartum depression [8]. The profound burden of LBW on newborns and caregivers makes it an important public health issue.

The burden of LBW occurs predominantly in developing countries. Sub-Saharan Africa accounts for 15% of all LBW cases globally, with a regional prevalence of about 14% [9]. The region also has the most people living with HIV in the world, about 23.5 million out of the 35.2 million people living with HIV globally [10]. HIV significantly increases the risk of LBW in sub-Saharan Africa [11, 12]. In Ghana, for example, the odds of LBW is more than six times greater in HIV-infected mothers than HIV-uninfected mothers [13].

Currently, the experiences of HIV-infected mothers caring for LBW infants in sub-Saharan Africa have not been reported. As a result, we lack detailed knowledge of what HIV-infected mothers go through when caring for LBW babies in a setting where they are stigmatized [14] and often poor [15]. Consequently, health professionals lack evidence-based knowledge and understanding of this population's unique experiences, and may be less able to provide high quality care and counseling to improve health outcomes, related particularly to the mental health of caregivers.

We also don't know how caring for LBW infants' shapes HIV-infected mothers' continuous engagement in HIV care in the postpartum year (defined in this dissertation as remaining in care for treatment and support services (retention) and adhering to antiretroviral therapy (ART)). This gap in knowledge is concerning, considering that caregivers of relatives with serious health conditions tend to be less likely to use preventive health services compared to non-caregivers [16], and because they prioritize the care for their sick family member (e.g. infant, spouse) over their own health (e.g. having time to see a doctor) [17]. Already, global retention rates in HIV care the postpartum year are disappointingly low [18]. In one study in Ghana, only 66% of HIV-positive postpartum women made one visit within the first six months after birth [19]. This is a problem because not following-up on HIV care means mothers do not have access to their anti-retroviral drugs. In addition, globally, adequate ART adherence declines from about 76% during pregnancy to 53% in the postpartum period [20].

Poor engagement in HIV care is associated with high mortality [21], AIDS defining CD4 cell count [22], and disease progression [21, 23]. For mothers who do not receive ongoing ART, high levels of viral load increases the likelihood of mother-to-child transmissions through breastfeeding [24, 25] and transmission of HIV to sexual partners, if sex is unprotected [26]. Thus, it is crucially important to understand if LBW additionally contributes to poor engagement in the postpartum period.

The relevance on LBW as a predictor of maternal postpartum follow-up in HIV care may be context specific, depending on the prevalence of LBW, the population it affects, structure of pediatric and HIV care, and the socio-cultural dimensions of having a LBW infant.

In Ghana, about 22% of mothers who are HIV-infected give birth to LBW babies compared to 15% among those who are uninfected [13]. Mothers with LBW infants in Ghana in general are often young (<35 years) [27] and have a low socio-economic background [28]. Having a LBW newborn could affect follow-up in HIV care in different ways. Poor engagement could result because of the following factors associated with LBW: 1) prolonged hospital status and frequent hospital visits for pediatric care at a facility that is disjointed from HIV care for the mother [29], 2) high psychological distress (mainly depression and anxiety) [8, 30], 3) caregiver burden [31], 4) low social support because of local perceptions of LBW being a result of maternal moral failure [32]. Though less studied, research in developing countries has shown that caring for a LBW infants can be a source of stigma toward mothers [33-35]. Stigma is a known contributor to disparities in health care use among people living with HIV [36].

Alternatively, better engagement could instead occur because 1) LBW can be a strong motivation for HIV-infected mothers to engage in care for themselves, and 2) frequent contact with health facilities could increase the likelihood of following-up in postpartum HIV care.

Given these uncertainties, it is important to explore how caring for LBW infants affect postpartum women's engagement in HIV care and the mechanisms that underscore that process.

Qualitative research methods are well suited to uncover processes by which events and actions occur and generate hypotheses [37]. Furthermore, interventions to improve follow-up rates among HIV-infected mothers with LBW infants, should LBW to

be found as an important factor, will require a thorough understanding of the mechanism that links birthweight to HIV care postpartum.

Based on these considerations, this dissertation draws primarily on qualitative research methodology to document the experiences of mothers living with HIV with LBW infants in Ghana, and examine how they affect their engagement in HIV care. To tease out the unique experiences of LBW mothers, it is important to broadly understand the challenges that postpartum women face with engagement as whole, and also how the experiences of LBW mothers compare to mothers with normal birth weight infants. The **specific aims** of this dissertation are:

Aim 1: To elucidate the main barriers and facilitating factors to retention in HIV care in the postpartum period among Ghanaian women.

Aim 2: To describe HIV-infected mothers' experiences caring for LBW infants in Ghana.

Aim 3: To explore how caring for a LBW newborn affects adherence to ART and retention in HIV care in Ghana in the postpartum year.

ORGANIZATION OF THE DISSERTATION

Chapter 1 of this dissertation provides the background literature and theoretical foundations of the study. The background focuses on the burden of LBW, caring for LBW infants, the role of HIV in maternal care for newborn, retention in HIV care and adherence to ART in the postpartum year. The theoretical foundation for this study draws broadly on literature from phenomenology, ethnomedicine (specifically illness etiology of and care-seeking for low birthweight), retention in HIV care, and mental health (mainly the role of depression, stigma in influencing use of preventive health services).

Chapter 2 is a description of the study setting. Chapters 3-5 are three separate manuscripts that correspond to the specific aims of the study. In Chapter 3, I take a broad look and explore the key challenges postpartum women face for retention in HIV care. I also elucidate on the prominent factors that participants in our study used to addresses these challenges. I devote Chapters 4 and 5 to describe the experiences of mothers with LBW infants and how they affect their engagement in HIV care. Chapter 4 focuses on stigma relating to newborn size and its effects on the mother. In Chapter 5, I examine how caring for LBW infants contributes to incomplete ART adherence and missed clinical visits for ART in the postpartum.

Chapter 6 is the conclusion section of the dissertation. I summarize the major findings and articulate the research and public health implications.

BACKGROUND

Low birthweight in Sub-Saharan Africa and Ghana

Adverse birth outcomes, mainly LBW and preterm birth, have been described as the biggest "drain on human capital in poor countries" [38]. Complications from low birthweight accounts for 40-80% of the 2.8 million neonatal deaths every year [38, 39]. LBW infants who survive are at risk of mild to severe morbidities, such as infections, jaundice, and poor neurological development [40-42]. These morbidities demand significant physical, mental, and emotional support from caregivers [43].

In Ghana, the prevalence of LBW is about 14% based on aggregate data from population-based [44] and hospital-based studies [28, 45, 46]. This estimate is similar to pooled data from studies conducted in Sub-Saharan Africa [9]. Across regions in Ghana, the prevalence of LBW ranges from 8.7% in the Brong Ahafo Region [45] to 21% in the Northern Region [47]. The national prevalence of 14% corresponds to approximately 108,640 babies per year, based on 776,000 births each year in Ghana [48].

LBW is mainly caused by preterm birth (i.e., gestational age <37 weeks) or intrauterine growth restriction (i.e., birthweight <10th percentile for gestational age) or both [49]. In Ghana, LBW is a problem that disproportionately affects poor and less educated women [28, 50]. In one population-based study, women of low socioeconomic status (i.e., low income, less than a high school education, and living in a poor neighborhood) were three times more likely to give birth to a LBW infant compared to those who were of high socioeconomic status [28]. In that same study, about 95% of the LBW cases occurred among women of low to middle socioeconomic status [28].

A reason for the disparity may be that the major risk factors for LBW in Ghana—malaria infection [47], poor nutritional status [27, 28], living in a rural setting [50], indoor

pollution (cooking with firewood and biomass) [46] —are pertinent among the poor and less educated. Whatever the explanatory factors are, what is clear is that LBW mothers in Ghana belong to a socially disadvantaged group.

HIV epidemic and low birthweight in Sub-Saharan Africa and Ghana

The HIV epidemic in Sub-Saharan Africa has significantly shaped the rate of adverse pregnancy outcomes [11, 12]. A sub-study of a meta-analysis showed that, in Africa, neonates born to seropositive mothers are twice as likely to give birth to LBW babies compared to those born to seronegative mothers [11].

In Ghana, the odds of having a LBW baby are six times higher for mothers who are HIV-infected compared to those who are negative [13]. About 1 out of 5 HIV-infected pregnant woman in Ghana will give birth to a LBW infant [13]. This proportion is troubling as more than half of all the 223,000 HIV-infected adults in Ghana are women of reproductive age [51].

The major HIV-related risk factors linked to LBW are HIV-disease progression (i.e. WHO clinical stage of HIV) [52-54], adherence to ART [55], low CD4 cell count [20], high maternal plasma viral load [56], and use of antiretroviral therapy [57-59].

The biological reasons why HIV contributes to adverse pregnancy outcomes are not completely understood [52]. One hypothesis is that HIV contributes to poor intestinal absorption of essential nutrients, reduced dietary intake, and metabolic abnormalities. These conditions cause poor growth in utero, resulting in growth restriction [60]. Another hypothesis is that HIV triggers a severe inflammatory response in utero, which results in a strong, unscheduled immune response [61]. This response causes severe inflammation

which can lead to premature birth [61], a leading cause of LBW [49]. Still, others have posited that low CD4 cell count may increase transmission from mother to child [62]. Pediatric infection restricts in infant growth in-utero [63], resulting in LBW.

Experience caring for low birthweight infants

The determinants of LBW in Sub-Saharan Africa and Ghana have been well studied. What has received less research attention is caregivers' experience caring for such infants [64]. We also have little data on how they live with and interpret their experiences. Studies on caregivers' experiences are critically needed because they help health care professionals identify the social and health care needs of caregivers and opportunities for intervention in the home or clinical setting [1, 65]. Studies on caregivers' experiences also help us understand the motivations and decision-making processes that underscore their health practices, such as adherence to treatment [66, 67].

Numerous qualitative studies have documented women's lived experience caring for LBW infants in general [1-7]. They have shown that a sense of alienation, prolonged hospital stay, psychological distress, and difficulties in caregiving are defining experiences for mothers with such outcomes [1-7]. These findings are not easily transferable to resource-poor settings as the majority of these studies have been conducted in developed countries [5, 6].

Some qualitative studies conducted in low-and-middle-income countries have suggested that mothers with LBW infants also experience stigma because of negative social views about their appearance [35] and future cognitive potential [34]. The problem of stigma relating to a baby size has, however, received scant attention in research conducted in Sub-Saharan Africa [33, 68]. Thus, little is known about the source,

characteristics, and effects of this stigma on caregivers. In particular, how this stigma influences mothers' health care use in the postpartum period is currently unknown. Investigating the effect of stigma is of public health significance because high levels of stigma lead to poor use of health and social services [36].

Living with HIV and caregiving

Maternal HIV-infection adds a layer of complexity to the experience of caregiving in general. In a meta-synthesis of qualitative studies on motherhood among HIV-infected mothers, Sandelowski et al. concluded that motherhood "aggravated the symptoms of HIV infection and intensified the stigmatization associated with it" [69]. Mothers living with HIV felt blamed that they were putting their babies at risk of infection.

This then motivated and impaired maternal-child relations. The authors also pointed out that living with HIV affected mothers positively by motivating them to "live, fight, get off drugs, care for oneself, and avoid risky behaviors" [69]. This stigmatization impaired mother-to-child relations and the motivations for positive behaviors associated with HIV create a unique context for a phenomenological experience of caregiving that may differ from other mothers who are seronegative or suffer from other chronic diseases. Sandelowski et al.'s review focused on caregiving in general among HIV-infected mothers. They do not identify or discuss caregiving experiences of HIV-infected mothers with adverse pregnancy outcomes.

LBW may heighten the stigmatization and maternal blame associated with HIV or flare up HIV-related symptoms due to the physical and emotional demands of caring for such infants, particularly those who are very low birthweight. Moreover, in resource-poor

settings, mothers must contend with poverty, limited access to medical interventions, social services, and mental health support. Thus, the concurrent impact of both HIV and LBW on caregivers in a resource-limited setting needs to be explored to identify and improve caregiver's well-being, a goal our research seeks to pursue.

Engagement in HIV care in the postpartum period in Sub-Saharan Africa

Two major challenges that threaten HIV-infected mothers' well-being during the postpartum year are poor retention in HIV care and non-adherence to ART. Retention in HIV care (i.e., continuous attendance at HIV clinic for prevention, support and care services) has proven to be a challenge in many countries [70, 71].

Poor retention in HIV care and ART adherence are both independently associated with HIV viral load [72, 73], which results in the mortality and morbidities related to HIV. Even missing one appointment in a year or being late for more than seven days to collect ARTs has been found to be positively associated with mortality [22] and high viral load [74], respectively. Missing two consecutive days of ARTs is also linked to a high viral load [75]. Owing to their significance for HIV viral load reduction, retention in care and ART adherence have become key cornerstones of the "treatment as prevention" approach to HIV prevention [76, 77].

Several studies indicate that engagement in HIV care rates are worse in postpartum women than pregnant and non-pregnant women [78, 79]. In a South African study, for example, 80% of mothers living with HIV remained in HIV care during pregnancy, but by six months after birth, this proportion dropped to 52% [80]. Among women living with HIV in the US, retention rates for HIV care in the first-year postpartum range from 37%-39% [18, 81]. Similarly, postpartum women in Ghana have

lower retention rates in ART programs than pregnant women [66% vs. 75%] [82, 83]. Disparities in retention rates have persisted even in the context of the WHO supported Option B-plus (requiring lifelong ARTs among pregnant women at the time of diagnosis) [84].

In Ghana, the recommended HIV care during the postpartum period requires at least six visits to a health center in a year. The first two visits occur at the postnatal clinic at two and six weeks after birth. At these initial visits, babies receive postnatal care and get tested for HIV, while mothers collect their ART and are evaluated for disease progression. Subsequently, the mother is transferred to a separate adult HIV clinic, where she should make a visit at least once every three months to come back for refills for ARTs. For women with clinical symptoms of HIV, additional visits, about once every two weeks, are required. Those who do not follow up on their care do not receive ART. A study in Kumasi found that 37% of postpartum women had not made a visit in six months to pick up their ART [82], demonstrating the unique challenge the postpartum period creates for engagement with HIV care.

The barriers to engagement in HIV care are numerous and vary significantly across countries and populations. Among postpartum women living with HIV, to date, the specific barriers they face remains unclear. Reasons that have been cited in the literature are intensive childcare [18, 82], less frequent contact with health facilities compared to during pregnancy [85], changes in maternal motivations before and after childbirth [20, 80, 85], low financial and social support from families and partners [85 79], fear of finding out about infant's HIV status, and mothers not knowing they had to return for care [86].

In the study in Kumasi, Ghana, the odds of poor follow-up (i.e. no visit in six months) were five times greater among women who did not complete the two recommended adherence counseling visits compared to those who did complete counseling [87]. While this finding suggests that the some of the problems that lead to poor retention may start before childbirth, they provide a limited understanding of the unique challenges in the postpartum period.

Another study in Ghana that included both pregnant and postpartum women showed that inadequate knowledge about prevention of mother to child transmission (PMTCT) among women also contributed to missed visits for ART [83]. It is not clear how PMTCT knowledge may contribute to variations in retention patterns during and after pregnancy. Our knowledge of the key challenges that postpartum women in Ghana face with follow-up in HIV care is extremely limited because of lack of data, particularly qualitative data.

Globally, adherence to ART is also a problem in the postpartum period. Once ART has been prescribed, depending on the regimen, patients may need to adhere to 54-95% of the ARTs to result in HIV viral suppression [72, 78]. A recent meta-analysis of 51 studies conducted in both resource rich and poor countries, demonstrated a drop-in ART adherence rate from 75% in pregnancy to 57% in postpartum [20]. They speculated economic and physical stresses, and postpartum depression may be additional reasons for lower retention in the postpartum period compared to during pregnancy [20].

Data on ART adherence among pregnant and postpartum women in Ghana remain scarce. In the most recent systematic review on adherence rates comparing pregnant to postpartum women, of the 51 studies, none was from Ghana [20].

Low birthweight and engagement in HIV care

To date, studies on engagement in HIV care after birth have not explored the role of infant health, including weight at birth. As noted earlier, LBW is a common characteristic of infants born to mothers living with HIV in Sub-Saharan Africa [11]. The relative significance of LBW on follow-up in postpartum HIV-care is unknown.

Research suggests that HIV-infected mothers with LBW children may have difficulty following recommended treatment plans [55, 88]. In a clinical trial on the use of nevirapine to prevent mother-to-child transmissions, pregnant women living with HIV in an urban setting in Zambia were given nevirapine to take home and ingest within 48 hours before delivery. At delivery, women who gave birth to LBW infants were 4.57 times more likely not to have taken their medications compared to those who had normal birthweight infants. They were also 2.33 times more likely not to have taken the medication at the right time relative to the same group [88]. This pattern extends beyond Zambia. Across four African countries, Stringer et al. also found that HIV-infected mothers who gave birth to LBW infants had 34% higher odds of not adhering to their treatments to prevent mother-to-child transmissions during pregnancy compared to those who gave birth to normal birthweight infants [55]. Though models of preventing mother-to-child transmission of HIV have changed since these studies, the data points to a sub-population that may already be facing challenges following recommended treatment plans.

A related issue concerns the mechanisms by which birthweight could lead to poor follow-up rates or ART adherence. Below, I lay out the potential pathways: psychological, institutional, and socio-cultural.

Psychological dimensions of caring for low birthweight infants

Across contexts, postpartum depression, caregiver burden, and maternal motivation to live and care for her child are plausible pathways between LBW and maternal engagement in HIV care. LBW significantly increases the risk of postpartum depression. In one study in Ghana, among mothers with such infants, the prevalence of mild, moderate, and severe postpartum depressive symptoms were 32.7%, 27.4%, and 9.8% respectively [8]. Thus, the prevalence of postpartum depressive symptoms in this group is about 70%, which is significantly higher than rates reported among mothers in general [89] and HIV-infected mothers specifically [90].

Depression among mothers with LBW children is thought to persist during the first year after birth [30]. Maternal HIV infection may exacerbate this high rate. Already, there is elevated frequency of postpartum depression in low-and-middle-income countries [91]. Depression is known to affect chronic care management and use of preventive health services [92] as well as ART adherence [93] .

Aside from depression, families who take care of sick infants (particularly very low birthweight babies) often experience high caregiver burden (emotional, financial, physical, and spiritual burden) [94] because of the many morbidities associated with LBW [1, 3]. Though less studied in pediatric care, caregivers of sick family members (such as those with serious, life-threatening conditions, chronic diseases like cancer, physical and mental disabilities) are less likely to use preventive services for their health (such as visiting a provider for primary care) [17]. Among people living with HIV in Sub-Saharan Africa, Ware et al. found that social and familial responsibilities are primary reasons why these patients' unintentionally disengage from HIV care [95].

Institutional care of low birthweight infants in Ghana

After childbirth, newborns in Ghana are discharged 24 hours after delivery if the baby is healthy. Infants with very LBW (<1500 g), at tertiary care settings, are sent to the neonatal intensive care unit (NICU) to be evaluated and monitored [29]. After discharge, mothers need to follow-up with a pediatrician for continued monitoring. Such frequent contacts should increase the likelihood that HIV-infected mothers with LBW babies would follow-up on their own HIV treatment. However, in Ghana, pediatric and maternal HIV-care are disjointed; thus maternal HIV care needs are not met during these routine visits at pediatric units.

HIV infection status of the child may, however, alter this institutional barrier. Once the infant is HIV-infected, both the mother and child receive HIV care at the same hospital unit. Maternal motivation to keep the infant alive may facilitate follow-up in HIV care for the infant and thereby the mother.

Socio-cultural dimensions of low birthweight in Ghana

The last potential dimension of LBW that may have a bearing on postpartum follow-up in Ghana has to do with its cultural interpretation. Among the Akans of Ghana, LBW is part of a traditional illness called *asram. Asram* is an umbrella term for 14 types of pediatric symptoms and conditions [96]. Pertaining to low birthweight, is the term *asram kotrɛ,* which literally means as small as a lizard. The causes of a*sram* within the local etiology of diseases are understood to have both supernatural (spirits) and personal components. Supernaturally, *asram* is caused by an evil-eye. At the personal level, maternal moral failings in adhering to dietary and behavioral regulations during

pregnancy are a primary cause [32]. Thus, there is an element of maternal blame and "stigma" associated with having such small babies and a resulting familial disengagement [32]. Whether HIV infection, with it associated stigma and social stressors, exacerbates this blame and stigma is unknown.

Emerging from this blame and understanding are three main consequences: 1) low familial support, 2) reluctance to bring infants into public spaces, and 3) delayed care seeking at health facilities because of seeking care at traditional healers [97]. In a cluster-randomized trial to promote skin-to-skin care, for example, researchers interviewed mothers with LBW infants about their experiences. A major finding was that mothers received low familial support in caring for their newborns [98]. Familial support is critical for postpartum follow-up because of its role in reducing caregiver burden [1].

In my own work [32] and that of others in Ghana [96], a key finding has been that a*sram* is considered not to be fully curable at health facilities; thus, mothers seek care from traditional medicine healers. Similar care-seeking behavior has been observed among mothers with LBW infants in rural Nigeria [97] and has been noted to delay maternal interaction with the formal health sector [96].

The contextual factors elucidated (delayed care-seeking and disjointed HIV and pediatric care) and the social (low familial support and maternal blame) and psychological impacts of LBW (high depression and caregiver burden) suggest that mothers living with HIV with LBW may have more difficulty following-up on HIV care visits for their own health compared to those with normal birthweight babies. Thus, they may be more likely to miss more postpartum follow-up appointments for HIV care. They may also have difficulty with ART adherence because of caregiver burden and

depression. My goal is to explore these issues and contribute to the understanding of the key factors that shape retention in HIV care in the postpartum period.

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CHAPTER TWO: GHANA—GEOGRAPHY, DEMOGRAPHY, CULTURE, ECONOMY, POLITICS, AND HEALTH

Figure 2: Map of Ghana

Source: http://www.ghanaweb.com/GhanaHomePage/geography/maps.php

SETTING

In this section, I provide a brief background about Ghana's population, ethnic, and religious composition. I then highlight major demographic, economic, and health indicators and transitions in Ghana. I conclude by discussing Ghana's political history and its impact on HIV, maternity and mental health services delivery.

Geography, Demography, and Culture

Ghana is a West African country that borders Ivory Coast to the west, Togo to the east, Burkina Faso to the north, and the Atlantic Ocean to the south. With a land mass of 238,533 sq km, Ghana is slightly smaller than the state of Oregon [1].

Demographically, the country is marked by a young age structure, declining fertility rate, and increasing urbanization. Approximately, 38% of the country's inhabitants are below 15 years old, and 19% is between the ages of 15 and 24 [1]. The national fertility rate has declined by more than 30%, from 6.2 children per woman in 1988 to 4.2 in 2014 [1, 2]. The country's population is approximately 26 million. From 2001 to 2014, the proportion of Ghanaians living in an urban area has grown from 36% to 54% [1].

Administratively, Ghana has ten regions, and each region is sub-divided into districts. Accra is the capital of Ghana with about 2.2 million residents [1].

The average life expectancy in Ghana has increased drastically, from 46 years in 1960 to 61 in 2014 [3]. A decrease in child mortality has underscored some of the improvements in life expectancy. From 1983 to 2014, for example, the under-five

mortality in Ghana was reduced by two-thirds, from 155 deaths per 1000 live births to 60 deaths per 1000 live births [2].

The population of Ghana varies significantly by language, religious practice, and ethnic group. The dominant ethnic group is the Akan-speaking group, which make up about 47.5% of the population [1]. Other large groups include the Mole-Dagbon (16.6%), Ewe (13.9%) and Ga-Dangme (7.4%)[1]. Ghana has over 24 different languages, but the Akan language, Asante Twi is the most widely spoken language; one in six people in Ghana speaks this language [1].

Religion permeates deeply into public and private spheres in Ghana. About 71.2% of Ghanaians are Christian; 17.6% are Muslim; and 5.2%, adhere to traditional beliefs such as ancestral worship and animism [1]. About 5.8% of Ghanaians indicate they have no religious affiliation [1]. According to Adinkrah, religious beliefs and practices intertwine with social and cultural events like naming, education, marriage, and decisions to seek and use health care [4]

Political and economic background on Ghana

Ghana was British colony until 1957. Post-independence, specifically between 1965 and 1993 the country's political history was tainted by military coups, political instability, and human right abuses [5]. In 1992, with internal and external pressures, Ghana adopted a constitution and allowed a multi-party system of democracy [5]. There have been four transitions of political power since then.

With the political stability and an oil discovery in 2008, Ghana was able to move from a low-income to a low middle-income country. From 2000 to 2014, the country's gross national income per capita more than doubled, from $390 to $1590 [6].

Consequently, Ghana has made significant breakthroughs in reducing several indicators of poverty. The country met several of the Millennium Development Goals relating to poverty, including cutting by half the proportion of people without access to safe drinking water and the aim to increase primary education [7]. Despite these achievements, about 28.6% of Ghanaians still live in poverty, [7] and 11.2% of youth ages 15-24 are unemployed [1].

Key health laws that impacted access to maternal, HIV, and mental health services

Between 2000 and 2008, health policy changes paved way for increased access to ART and maternity services in Ghana [8, 9]. The New Patriotic Party succeeded the National Democratic Party in 1996, and ruled Ghana until 2008. During this period, the government introduced legislation that shaped Ghana's response to the HIV epidemic and structured its health insurance system.

In 2002, the government set up the multi-sectoral, supra-ministerial body known as the Ghana AIDS Commission [10]. The Commission is the highest political body regarding HIV and AIDS prevention and control in Ghana. It provides leadership and coordinates all HIV-related programing in the country. The Commission works through the Ghana Health Services, Regional and District Level HIV Committees to deliver HIV-related programming [10].

In partnership with international donor agencies, the Commission implemented several policies that expanded access to ART. Antiretroviral therapy is now provided free of charge for people living with HIV. Also, delivery of HIV care, which used to be only available in tertiary and regional level hospitals, was decentralized [9]. This paved the way for district level hospitals to offer ART treatement, benefiting those in rural areas. Moreover, the commission strategically committed resources to PMTCT of HIV. Thus, between 2009 to 2012, 90% of pregnant women living with HIV were on ART to PMTCT, and the incidence of HIV in women was cut by 50% [11].

In 2003, the government also introduced the progressive National Health Insurance Scheme (NHIS) Act 650 in 2003 [12]. The goal was to provide universal access to health care to all Ghanaian citizens [13]. The NHIS replaced a "fee before service" system of health care, which is popularly known in Ghana as the "Cash and Carry" system. The system, endorsed by the World Bank through its Structural Adjustment Program, had stifled access to health care by increasing costs for patients [14].

The NHIS is financed through a combination of yearly premiums, taxes, government investments, and donor funding [12]. The cost of the premium per person was designed to be sensitive to those with low or no income. The NHIS exempted all those who have proof of no income, are homeless, are not living with someone who was employed, or are over the age 70 [12]. An individual's income level used to determine their premium cost; however ,the NHIS recently began to chargea flat fee of about $2-$3 per person per year [12].

One essential part of the NHIS is that it covers all maternity care services, including cesarean sections. The free access to maternity care may have contributed to

the substantial declines in home births in Ghana, from 53% in 2003 to 26% in 2014 [2]. In urban regions, such as Greater Accra, where this study was conducted, only 7% of births occur at home [2].

Since 2009, the NHIS has encountered significant financial problems, including non-reimbursement of facilities for services. Consequently, news reports suggest that several hospitals are now re-introducing the "Cash and Carry" system [15].

Reverting back to this system will have a profound impact on the affordability of health care, particularly among pregnant women. I witnessed firsthand during data collection for this study how the current failings of the system was impacting mothers. Some of our participants were detained at health facilities because they could not pay their health care bill after giving birth. For some, their families were in debt because they had to borrow money to pay the cost associated with childbirth. All of these women had already paid their premiums under the NHIS (see Chapter 3).

The New Patriotic Party left power in 2008 and was replaced by the National Democratic Party. The government, in 2012, passed the human-rights oriented Mental Health Law, Act 846 [16]. The most notable part of this law is that it mandated that mental health services be integrated into primary health care or community based care. It also made formal provisions for funding for mental health through the Ministry of Health [16].

Prior to the law, mental health in Ghana was primarily delivered at tertiary hospitals and mental health institutions. Mental health specialists provided most of the services and patients with serious mental conditions were the ones who were prioritized [16].

The changes to mental health in Ghana is significant to the study population of this dissertaton. Mothers with sick newborns, including low birthweight and preterm infants, have the highest rate of depression reported among any group of women in Ghana to date [17-19]. Through this law, there is hope that mental health can be provided at the primary care or community level and funding mandated to go into such services may improve access to care in the near future.

In summary, Ghana has had economic growth and political stability in recent years. The country has also passed progressive health policies. These achievements have resulted in free access to ART and increased utilization of maternity services. An important step was lesgislation mandating integration of mental health services into primary health care. Currently, one big threat to Ghana's health system is the fiscal health of the National Health Insurance Scheme.The next chapter of this dissertation is the first of three separate manuscripts. The data for all the three papers are from the same source: interviews with 30 postpartum women living with HIV in Accra.

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CHAPTER THREE: KEY BARRIERS AND FACILITATING FACTORS OF RETENTION IN HIV CARE AMONG POSTPARTUM WOMEN LIVING WITH HIV IN GHANA

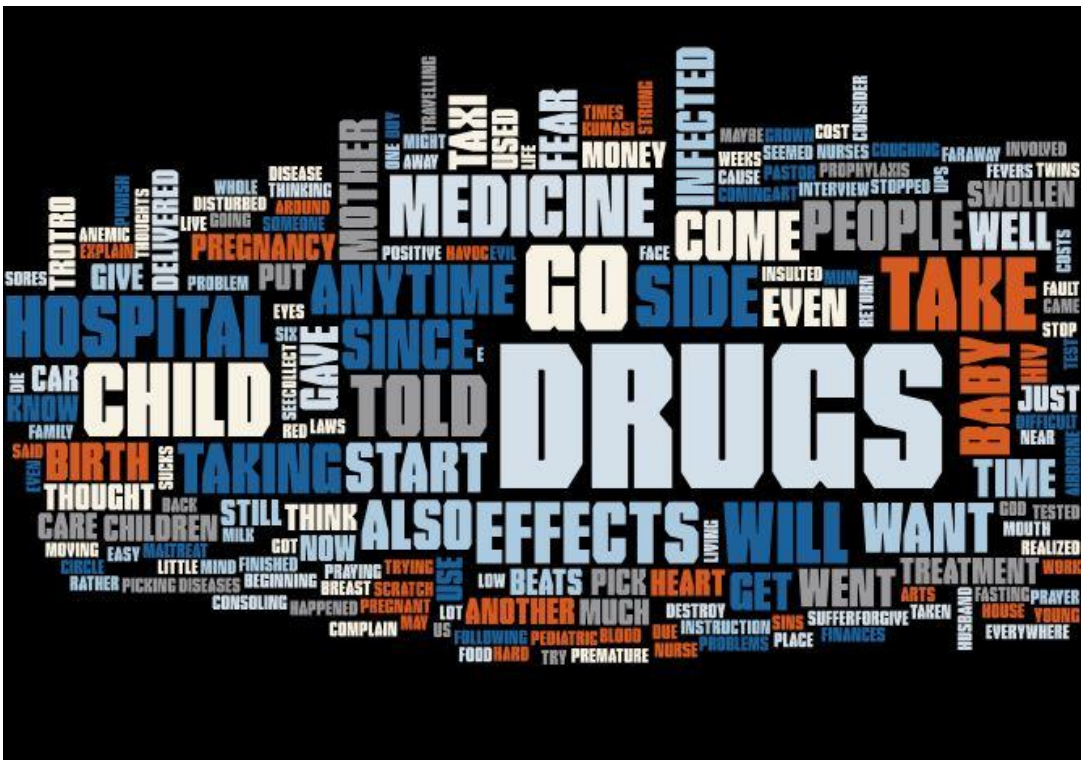

Figure 3: A word cloud of participants' quotes used in the manuscript below

Title: Key barriers and facilitating factors for retention in HIV care among postpartum women living with HIV in Ghana

ABSTRACT

Background: Retention in HIV care has been shown to be lower in the postpartum period than during pregnancy, but the reasons for this observation are poorly understood. We examined barriers and facilitating factors to retention in HIV care in the postpartum period in Ghana.

Methods: We conducted semi-structured, in-depth interviews with 30 postpartum women living with HIV in Accra, Ghana. We recruited participants from two tertiary facilities implementing Option B-plus for prevention of mother-to-child transmission. We compared the experiences of mothers who had and had not disengaged from care to identify key barriers and facilitating factors.

Results: Mothers reported several barriers to care and how they overcame them. ART-related side-effects and transportation costs were the two major barriers mothers reported. A majority of new mothers indicated that concern for their newborns' wellbeing obligated them to take taxis to receive care. This introduced a financial burden to access care, a burden that was further exacerbated by HIV-related stigma, as mothers reported choosing HIV treatment centers farther away from where they lived to avoid being stigmatized. A few of the participants' stories showed that an experience of ART-related side effects during pregnancy created a reluctance to return to care in the postpartum period. Reported factors that supported continued engagement in care revolved around three major facilitating factors: 1) motivation to prevent mother-to-child transmission, 2)

perceived benefit of ART to maternal well-being, and 3) sufficient financial resources in the household.

Conclusion: For sustained improvement in retention in HIV care in the postpartum period, a multifaceted approach that reduces the financial burden of accessing HIV care, improves management of ART-related side-effects, and tackles stigma is needed.

Keywords: postpartum women, Ghana, qualitative, retention, HIV, antiretroviral therapy

INTRODUCTION

Ghana, like most sub-Saharan countries, has significantly expanded access to antiretroviral therapy (ART) among pregnant women [1]. About 90% of pregnant women living with HIV in Ghana are on ART for their own health and to prevent mother-to-child transmission (PMTCT) [1, 2]. Despite this progress, about one third of pregnant women living with HIV in Ghana will not make the required two visits to a health facility to receive ART in the first six months after birth [3]. Similarly, low retention rates in the postpartum period have been reported in a number of countries globally [4-7] and several reports suggest that retention in HIV care is worse in the postpartum period than during pregnancy [4, 7, 8]. In Ghana, for example, the retention rate in ART programs among pregnant women is 75% compared to 66% among postpartum women [3, 9].

Retention is closely associated with increased risks of mortality, HIV disease progression, and mother-to-child transmission. At 18%, Ghana has the eighth highest rate of mother-to-child transmission of HIV (including during breastfeeding) among the 21 sub-Saharan countries that constitute the UNAIDS' Global Plan priority countries [1]. The average mother-to-child transmission rate among the 21 countries is 14% (12-16%) and ranges from 32% in Chad to 6% in Botswana. One reason cited for the high rates across these countries is low retention in HIV care to receive ART in the postpartum period [1].

The reasons for lower retention in the postpartum year remain unclear. One theory is that motivation to remain in care decreases after delivery as mothers may be less concerned about their children getting infected with HIV than during pregnancy [10, 11]. Others have suggested that pregnant women are more likely to visit health facilities for care compared to postpartum women, visits that maximize opportunities for engagement

[12]. Another barrier may be that mothers believe that their own HIV care is not as important after their babies are born and they are not infected [13]. Our ability to characterize the reasons for retention loss after delivery is compromised by research approaches that combine the experiences of pregnant and postpartum women [12].

The lower retention rate after delivery suggests that postpartum women may have unique challenges [10], but descriptions of the experiences of women who fall out of care after initiation of treatment are lacking. We used a qualitative design to draw on the experiences of Ghanaian women living with HIV, to understand barriers to retention in care in the postpartum period. We sought to describe key facilitating factors that empower women to overcome barriers to remain in care.

METHODS

Setting

This study was conducted in the Greater Accra Region of Ghana. Ghana is a lower middle-income country with about 24.2% of its population living below the national poverty level [14]. The HIV prevalence in the country is 2.0% and 2.8% among pregnant women [15]. The Greater Accra Region is one of the ten regions in Ghana and has the country's largest city, Accra. With an HIV prevalence of 3.8 %, the region ranks third among the ten regions in the number of people living with HIV [15].

Study participants were recruited from Korle Bu Teaching Hospital (Korle Bu) and Ridge Regional Hospital (Ridge), two tertiary hospitals located in Accra. Korle Bu is the largest HIV treatment center in the country with about 25,000 patients per year. At both facilities, pregnant women are routinely tested for HIV during antenatal care and referred to an adult HIV treatment center, called *Fevers* at Korle Bu and *ART Treatment*

Center at Ridge. Based on the World Health Option B-plus model [16], women who test positive are provided lifelong ART, irrespective of their CD4 cell count. At both hospitals, free ART is provided to patients typically at three month intervals. Adult and pediatric HIV care are provided in separate buildings at both hospitals. Antenatal care and postnatal care are also separated geographically, in different buildings from the HIV care, though counselors at the antenatal clinic perform HIV tests.

In Ghana, mothers living with HIV are expected to make several visits for HIV, maternal, neonatal, and child health services in the first year after birth. Because the drugs are given in 3-month intervals, they must attend at least four visits at an HIV treatment center for full treatment. These appointments exclude any visit for laboratory tests, like CD4 cell count, which are done at least once a year at the two hospitals. For their children's health, they are expected to attend two routine postnatal care visits and three separate visits at 6 weeks, 6 months, and 1 year for an infant HIV diagnosis. For each of these three visits, they have to visit twice: once for the test procedure, and once again to receive the results.

Study Participants, Sampling and Recruitment

Study participants were 30 urban, adult, postpartum women living with HIV who had delivered at the two hospitals. The eligibility criteria were: living with HIV, gave birth at or were receiving HIV treatment at the two hospitals, were 18 years or older, and had an infant under one year of age. The aim of this paper was nested in a qualitative project that sought to explore influence of birthweight, as a marker for infant health, on retention in care. Thus, participants were purposefully sampled based on their infants' weight at birth (low birthweight/normal birthweight). For this aim, we also sampled

based on time since childbirth, and last visit for HIV care. The latter was designed to get the perspectives of those who had prolonged disengagement from care.

Participants were recruited from the adult and pediatric HIV treatment clinics, antenatal and postnatal clinic, and neonatal intensive care unit via nurses, midwives, and HIV-related counselors. In each unit, health workers were briefed about the study's goal, procedures, and eligibility criteria. Interested patients who met the eligibility criteria were referred to a study team member, who provided more details about the study and enrolled the potential participant. In addition, the two facilities also had contact information of all mothers living with HIV who gave birth at their facilities. With permission from the facility heads, a health worker telephoned the mothers and described the study to them. The contact information of those who were interested was forwarded to a female member of the study team who was a previously trained ART counselor with significant experience working with people living with HIV.

Data Collection

Participants were interviewed at the recruiting hospitals or in their home using a semi-structured interview guide. The interviews were conducted in Twi or Ga by two trained research assistants (male and female) or the first author in a private space. Interview topics included experiences with living with HIV, ART adherence, reasons for remaining in or leaving care, HIV disclosure, and the relationship between motherhood and HIV care. Interviews generally lasted about 30 minutes and ranged from 20 to 75 minutes. All the participants were interviewed once, except for two women who were interviewed twice to clarify issues discussed in the first interview. All but four of the interviews were audio recorded; handwritten notes were taken in the interviews that were

not audio recorded. Audio tapes were transcribed verbatim. Participants also completed a structured questionnaire on socio-demographic characteristics and HIV history.

To ensure quality of data collection, the interview guide was pilot tested with four mothers before its implementation. The research assistants were trained for a week on qualitative interview techniques, research ethics, writing memos and data collection procedures. In addition, after the first four interviews, each interviewer listened to the audio tape of their own interviews and that of the others. This exercise allowed the interviewers to compare their techniques to that of the others to fine-tune how they phrased questions and probed to elicit in-depth responses. Data collection occurred from February to April 2016.

Analysis

Qualitative data analysis occurred concurrently with data collection. After the first seven interviews, the research team met to discuss the emerging themes. A working theory was formulated about the major factors enabling and serving as barriers to retention. We then used new interviews to confirm, reject, and refine various aspects of the working theory during regular debriefing sessions as well as to tailor our sampling.

After data collection, more formal coding of the interview transcripts was carried out. The first author developed a codebook inductively based on the first five interviews and from concepts that emerged from the debriefing sessions. The codes were then systematically applied to the rest of the interviews. Codes were modified as needed to clarify boundaries and ensure consistency of coding. Incidents relating to reasons for keeping clinical appointments, prolonged disengagement from care, and missed visits

were extracted and more focused coding was done to identify underlying barriers and facilitating factors. Using the constant comparison method [17], each barrier was compared to others to delineate how they were connected within and across interviews. This comparative method was also repeated for facilitating factors.

Informed by Ware et al.'s work, we took an interpretive approach to this analysis to identify underlying concepts beyond the listing of the key barriers and facilitating factors [18]. We identified two separate stories from the interviews that provided a nuanced understanding of the key themes. Memos were written to elucidate themes and analysis. The overall analysis was informed by grounded theory [19] and managed using Atlas.ti [20].

Ethics

All participants provided a written informed consent before enrolling in the study. Each participant received an equivalent of $3 USD to compensate for time and travel. Additionally, they each received a diaper for their babies. The study protocol was approved by: 1) the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No. 6651), 2) the Ethical and Protocol Review Boards of the Ghana Health Services (ID:Ms-Et/M.2-P4.1/2015-2016) and 3) the University of Ghana Medical School (ID: GHS-ERC 16/09/15). All women who were no longer receiving treatment were encouraged to re-engage in care.

RESULTS

On average participants were 35 years old [range, 24-44 years], had two children, were five months postpartum, and had been on HIV treatment for 3.8 years. Eight of the

30 mothers were diagnosed with HIV during pregnancy and 21 were diagnosed before pregnancy.

All but one of the participants lived with a partner. About a third had more than primary school education, and three-quarters worked as small business traders or seamstresses. Six of the mothers had not-followed up on their HIV care in the postpartum period for between two and seven months. Eight of the participants had missed at least one visit for HIV care in the postpartum period.

Overview of themes

Drawing from our interviews with those who reported remaining in HIV care and those who did not, mothers reported several barriers to care and how these were overcome. ART-related side effects and transportation costs were the most central to their experiences and also related to other barriers (e.g., childcare, HIV disclosure).

Reported successes for overcoming barriers revolved around three major facilitating factors: 1) motivation to prevent mother-to-child transmission, 2) perceived benefit of ART to maternal well-being, and 3) sufficient financial resources in the household.

To contextualize these barriers and provide illustrations of the facilitating factors, we present case narratives from the lives of two women, who we will call here Hawa and Matilda (pseudonyms). We chose their stories because they were illustrative of the experiences of the women overall in our study who had stopped receiving HIV care for themselves. We first describe Hawa and Matilda's stories and then report the key themes that emerged across all women.

Origins of disengagement from HIV care in the postpartum period

Hawa's story

Hawa indicated that she intended to attend her clinical appointments for HIV care in the postpartum period, but that poverty served as a barrier. After the birth of her baby girl, she involuntarily stayed an additional 7 days at Korle Bu Hospital because she was unable to pay her medical bills: "*I was discharged on the 28th of December, but I did not have money [to pay the hospital bills], so I was still there [at the hospital]."* Hawa's family was in debt because they had to borrow money to pay the hospital bills: "*My husband…has to find money to settle the debt we incurred from borrowing money from others to pay for the hospital bills [for the new baby]*.

Since childbirth, Hawa had not made a follow-up visit to the HIV treatment center to receive ART for her own health for about three months because she "did not have money for transportation". She had stopped going to the HIV treatment center a month prior to childbirth for the same reason, so she did not have access to ART throughout the entire period of her hospital stay.

Transportation costs were difficult for Hawa because she lived about two and a half hours away from Korle Bu. "From here [my home] to town is so far," she explained. She also was not earning any income because she took an unpaid "maternity leave after birth." Some women in our study relied on financial support from their partners for money to cover transportation costs, but Hawa never reported to the interviewer that she asked her partner for money. She had not even disclosed her HIV status to him. In addition, Hawa described her husband's job as "not lucrative."

Hawa also had little social support from her in-laws and her mother, so she lacked help with taking care of her baby:

> *I don't want my people [in-laws family] to know [about being infected with HIV] because my people are very difficult. Even my mother has not been here to see me since I gave birth…because, there was a problem before [they insulted my mother], so my mum does not want to come near me.*

Hawa had planned to seek HIV care on the day of her interview: "*When you said you were coming with a car (to interview me), I thought I could return with you to the hospital to collect my drugs and come back."* Hawa's first husband had died of HIV. She was concerned about not being on treatment: *"That is why my heart beats anytime I start to think [about my treatment]."*

Matilda's Story

Matilda's experiences illustrate how ART-related side-effects during pregnancy led to reluctance to return for HIV care in the postpartum period.

She was diagnosed with HIV during pregnancy and reported being put on treatment without counseling regarding the potential side effects of ART: *"They too did not take their time to explain the side effects of the drugs to me…When…I tested positive, they just put me on the drugs."* She reported diligently taking her ART until one morning,

she woke up with a "*swollen mouth," "sores all over [her] face,"* and *"swollen red eyes*". Matilda initially thought the symptoms were because *"someone [evil] was trying to cause havoc and destroy her pregnancy,"* so she relocated from Accra to Takoradi to live in a pastor's house and seek a spiritual intervention.

One day, Matilda went for antenatal care and she said *"they realized I still had my drugs and told me not to do that again [stop taking my drugs]."* She was "*low on blood [anemic]*" because she had been *"fasting and praying".* A midwife's enquiry about her physical state led to the discovery of her non-adherence. Her ART regimen was eventually changed for her, but the new one also made her *"scratch [herself] a lot,"* so she stopped taking them.

Matilda stayed with the pastor until she gave birth, having already been out of treatment for two months. She recounted how she disengaged from her care for five more months after childbirth:

> *All that while [living with the pastor], I was not taking my medicine [ART]. It was when I gave birth to her that I went to the hospital. They told me that since the child sucks [breast milk] from me, I had to take the medicine and give six weeks [of] medicine [pediatric HIV prophylaxis] to the child as well. It was just around that time that we [the baby and I] were also moving to Kumasi [to live with my mother]. So their instruction was that if the medicine got finished, I should go to any hospital and get my medicine.*

But when I went there, they did not it give to me. They seemed to maltreat me, so I stopped following-up after that.

Key Barriers and Facilitating Factors for Retention in Care

ART-related side effects and motivation to prevent mother-to-child transmission

Matilda's experience with ART-related side-effects was echoed by several other participants. ART-related side-effects were the second most common reason why mothers had stopped following up on their care or reported missing a visit.

Their stories indicated that a fear of re-experiencing side-effects created a reluctance to return to care after birth. One mother, who had not followed-up on her HIV care for six months after birth, expressed this fear:

Because I suffer when I take the drugs, due to the side effects, anytime I thought of going for the drugs then the thoughts of the side effects came to my mind and they disturbed me. They put fear in me as well. I was also thinking that maybe because I was pregnant that was why I had those side effects.

In addition, most of the participants' stories suggest that the experience of side-effects created an environment where it was easier for mothers to disengage from care when they faced other barriers like mistreatment by health workers (as in Matilda's story). In another example, one mother disengaged from care for about two months in the

postpartum period. After she was diagnosed during pregnancy, she reported being adherent to her ART, even though she believed she was not infected. When she started experiencing side-effects, she reported to health workers to have the drugs changed. When they advised her instead to continue taking the ART because the drugs are associated with side effects, she stopped going for treatment. She only resumed treatment in the postpartum when a midwife encouraged her to take her ART because of the baby, though she still did not believe she had HIV.

> *I told the nurses that I was having the problems [i.e. side-effects from ARTs]. They told me that is how it is at the beginning when you start taking the drugs, and then, they will go away. I still did not take it after that. Then after pregnancy, when I gave birth, the nurse told me to take it because of the baby. That is why I am taking it.*

A few of the mothers in our study held contradictory beliefs like this participant. They said that they did not believe that they were infected with HIV, and yet, they took the ART. Their narratives indicate that sometimes the disbelief was an expression of faith in God to heal them. Other times, it was because they did not know how they became infected with HIV, so they were not convinced about the results.

One common glue that held these contradictory views together was motivation to prevent mother-to-child transmission (PMTCT). As the quote above shows, PMTCT can play an enabling role, helping mothers to re-engage in care despite disbelief in HIV

diagnosis and experience of ART-related side effects. This motivation was also the most common reason mothers offered for remaining in care in the postpartum period.

Based on the interviews, one primary factor that contributed to this motivation was the view that pediatric HIV infection results in undeserved suffering for the child; i.e., the need for and stress of lifelong ART adherence. Consequently, many of the mothers shared that retention in care was a kind of maternal sacrifice to free their children from suffering.

> *We went in for the test and he [the baby] was not infected. It was my prayer that God would forgive me, even if I was at fault. He should not punish this child for my sins…Even with us, grown-ups, it has not been easy taken the drugs, how much more this little child who will be on the drugs for his whole life?*

Transportation cost and sufficient financial resources

Apart from side-effects, transportation costs were the major reason for why women who had initiated care during pregnancy discontinued in the postpartum period.

As in Hawa's case and a few others, this was sometimes simply the result of insufficient financial resources in the household; they had stopped working or were in debt from childbirth.

However, participants also said that in the postpartum period, particularly during the first six months, maternal motivation to ensure newborn well-being made them feel

obligated to take a taxi to attend clinical appointments rather than the cheaper, more crowded, local bus called *trotro.* They feared the newborn coming in contact with others and risking becoming ill. In contrast, many participants reported taking the *trotro* during pregnancy to collect their ART. Thus, the financial cost of accessing HIV care was higher in the postpartum period than pregnancy, which negatively affected the ability of poor women like Hawa to seek care. One mother whose baby was about a month old captured the change that occurred with transportation preferences before and after childbirth.

> *Now that I have delivered, I have to come by a taxi, but before, I used to come here [Fevers] by trotro. I used to pick trotro from my house to Circle and then I pick another one to the hospital, but because the baby is young, I go to the hospital by taxi.*

Mothers explained that their preferred private over public transportation: "*There may be airborne diseases in the car since people might be coughing and the child too happened to be a premature child, I did not want her to get infected by any disease."* Culturally, the postpartum period is seen as a vulnerable period for a newborn to be infected with *Asram*, a local illness that is caused by an evil eye [21]. As a result, others might chastise mothers for walking long distances with a baby. These sociocultural pressures, combined with insufficient financial resources to meet these expectations, resulted in mothers like Hawa staying home.

Anytime I take them [the twins] out, people complain that why am I travelling with them to a faraway place. Now that my finances are also down, I have to be picking a taxi with them everywhere I go, and that is also another cost. Since I delivered, I do not have much money on me, so if I consider all the costs involved, then I do not go at all.

Distance was a key factor influencing the cost of transportation. The majority of the participants described intentionally seeking HIV care farther away from their homes to avoid HIV-related stigma— i.e. being recognized by their neighbors at the HIV treatment centers. As a result, transportation became even more costly because of the distance and pressure to take a taxi. One mother, who lived in the same town as Hawa explained her decision about where to seek care:

They asked me in which suburb of Accra do I live? I told them Kasoa. They suggested two options to me: I could routinely collect my drugs at Korle Bu or Winneba. I told them Korle Bu because if I choose Winneba, people may recognize me because I am a hairdresser.

The women who were able to obtain adequate resources to cover transportation reported receiving funds from either their own wages or from their partners. Social support from relatives for child care was also beneficial, as it allowed them to take a taxi

rather than a trotro if they could leave their infants at home with another caregiver. A few of the mothers, however, described not having this support because they did not want to disclose their HIV status to their relatives. One mother explained:

> *One week after I delivered, I took a taxi there [to the HIV treatment center] and she [a nurse] asked me whether there was no one at home to take care of the baby for me. Because I didn't want anyone to know where I was going, I took him [the baby] along. At the time, my in-laws and my mother were around and I told them that my husband had asked me to come to his shop… Afterward, the woman [nurse] paid for a taxi to take us back home.*

Perceived benefit of ART to maternal overall wellbeing

Another influential facilitating factor that helped mothers overcome barriers to retention in the postpartum period was the perceived benefit of ART for her own well-being. Most mothers' evaluation of this benefit often extended beyond health (survival and being healthy) to include social benefits like avoiding stigma and being able *"to care for their children."* Regarding stigma, one mother stated:

> *I have to go for my drugs because that is what protects me and if I do not have the drugs, I could die. Also, it could*

manifest that people will see and know the kind of sickness that I have.

About a third of our participants strongly perceived the benefits of ART. They often used phrases like *"my drugs are dear to me"* or *"I don't joke/play with my drugs"* or *"I take my drugs seriously"* to describe the value of ART to them. All of them viewed the drug as something they could not live without. Their stories suggest that they attached a high value to taking ART. For some of the mothers, significant HIV related morbidity prior to a formal diagnosis, or loss of a relative due to HIV/AIDS, led to this belief. In contrast, among those who had disengaged from care, none (with the exception of Hawa) reported any serious personal or familial clinical history of HIV prior to her diagnosis.

It's like the medicine has become my life. Without it, you cannot live. So, as for my drug, I take it because it is what is keeping me alive. Even when I make a mistake and it passes the time I was supposed to have taken the medicine, five minutes even, it really worries me. I do not play with my drugs.

I take my drug every day… The disease brings fears…I lost my daughter because of this sickness… She was 17 years old when she was first diagnosed… Then I realized that I

couldn't run away from coming to the hospital [for treatment], so I am so careful with this disease.

The majority of the mothers who perceived the benefits of ART often reported overcoming several barriers to retention, including mistreatment by health workers, transportation costs, and long queues. Some mothers reached out to others for money for transportation to get care and sacrificed basic physical needs to access and take their ARTs: *"When my time is up, I try hard to go. Even if I have to use the money to buy food, I use it rather to go for my drugs."*

Interestingly, several of the mothers who had missed visits or disengaged from care were concerned about their own health, particularly fearing death and leaving their children.

It is my husband who has been consoling me that all will be well... At times, I start to fear again and my fear is that I don't know who will care for my children if I should die…That is why I want to get my drugs so that I will be strong and work and care for my children too.

Hawa was concerned about her health as well as she knew firsthand the impact of HIV after her husband's death from HIV. She said, "*my heart beats anytime I start to think [about my treatment]"* despite the fact that her financial challenges limited her ability to get HIV care.

DISCUSSION

In our interviews with postpartum women living with HIV in Ghana, we found that disengagement from HIV care often starts during pregnancy, with ART-related side effects being one reason for disengagement. In the postpartum period, concerns about newborn health and HIV stigma contribute to disengagement by influencing the mode of transportation, and therefore cost, to access care. Motivation to prevent transmission to the baby, adequate financial resources, and perceived benefit of ART helped mothers stay engaged in care in the postpartum period. Our findings suggest that interventions to improve retention in the postpartum period may need to start during pregnancy. They also indicate that transportation costs as a contributor to retention loss after childbirth may only be a symptom of deeper problems. The core problems are social, cultural, and economic forces around optimal childcare, HIV stigma, and poverty.

Our finding that transportation cost is a prominent barrier to retention in HIV care is consistent with other studies conducted among adults living with HIV in sub-Saharan Africa, including pregnant and postpartum women[22-26]. In a qualitative study of postpartum women living with HIV in South Africa, not having money to take a taxi was one reason cited for women not following-up on their HIV care after birth [13]. In this setting, we found that transportation costs rise post-delivery as a result of sociocultural pressures obligating women to shift from public to more expensive private transport options, a previously undescribed phenomenon. Further, we found that maternal concern about newborn well-being and stigma associated with HIV are additional reasons for retention loss, as they affect the mode and costs of transportation.

Previous studies conducted in multiple sub-Saharan African countries have found that some women avoid attending HIV clinics because they do not want their HIV status to become known to either family members whose help they would need to access care or to community members who may see them using an HIV facility close to home [23]. We found that fear of HIV-related stigma influenced some mothers in our study to choose an HIV treatment center farther away from their homes. The distance, however, also exacerbated transportation fares and became an additional barrier in the postpartum period.

Some women did not disclose their HIV status to partners or relatives, despite being a potential source of financial support for transportation. Fear of divorce and abuse [12, 27, 28] may be one reason for non-disclosure to their partners [28]. Some mothers reported non-disclosure led to difficulties finding child care, thus precluding them from utilizing less expensive modes of transportation to receive HIV care. In multiple sub-Saharan African countries, lack of child care support has been found to be a barrier to retention in HIV care in the postpartum period [29].

Our finding that the degree to which women perceived the self-beneficial nature of ART regimens motivated retention in the postpartum period is consistent with other research [7]. In a retrospective cohort study of 21,930 pregnant and postpartum women in Malawi, for example, Tenthani et al. found that women who were put on ART for their own health (CD4 cell count <350 cells/mm3) were less likely to be lost-to-follow-up compared to those who were receiving care solely with intent to prevent maternal to child transmission [7].

Contrary to a prior study of postpartum women living with HIV in South Africa [13], in our setting, mothers not accessing HIV care remained concerned about their own health. In the former setting, interviews suggested that disengaged mothers no longer perceived the benefit of ART to themselves once their babies were born [13]. This conclusion was based on mothers who were already engaged in care. In contrast, we found that lack of financial resources and a fear of re-experiencing ART side-effects and stigma were more prominent barriers to retention. Future studies are needed to confirm the transferability of our findings to other sub-Saharan African countries, as it appears that views regarding benefits may vary by country.

Our findings should be evaluated in the context of our study's strengths and limitations. While we benefited from including perspectives from women who had disengaged from care, thus allowing direct comparison between different experiences, the number of such women in our study were few. As a result, we possibly did not reach saturation regarding reasons for disengagement from care and other barriers may not have been captured. In addition, our sample only includes urban women who delivered at a health facility and were receiving HIV care at tertiary hospitals. It is possible that rural women in Ghana or those receiving HIV care in a non-tertiary hospital may have different experiences or barriers and enablers e.g. women who live in rural areas may not face the same types of transportation constraints as urban women, for example, high taxi fares. Strengths of our study include recruitment from two large hospitals in urban settings. Retention in major hospitals and also among urban populations have been shown to be poorer than in small hospitals or among rural populations [23].

This study is one of the very few studies that uses a qualitative approach to delineate key barriers and facilitating factors to retention in HIV care for women in the postpartum period. Using this methodology, we were able to incorporate the perspectives of postpartum women who have disengaged from HIV care.

Our results suggest that interventions to improve postpartum women's retention in HIV care should be multifaceted. They should seek to decrease the economic burden associated with accessing ART, minimize the effect of stigma, and improve management of women who experience ART-related side-effects.

Ways to reduce the financial cost of accessing ART include reducing the costs of transportation to access HIV care or increasing the economic resources of families needing care. For the latter, a traditional microeconomic intervention like cash transfer could be one approach. In a randomized control trial in Uganda among adults living with HIV, the intervention group received an equivalent of $5-$8 toward transportation costs to receive ART. Lost-to-follow-up was about 50% lower in the intervention group (18%) compared to the control group (34%) ($p=0.04$) [30]. To minimize the burden of transportation costs, hospitals could also further extend the length of refills for ART in the postpartum period from three to six months. This flexibility may provide mothers more time to save money for their visits. Six months is also about the age mothers often feel comfortable to take public transportation with their newborns. In addition, counseling of women living with HIV during pregnancy should encourage savings toward transportation cost for HIV care visits in the postpartum period. This recommendation can easily be incorporated into counseling on birth preparedness currently offered to pregnant women as part of focused antenatal care [31].

To address the effects of stigma, policy makers could consider integrating HIV treatment for mothers into health services offered in the postpartum period for mothers and children. This may involve expanding where mothers can access ART to include maternal and child health service delivery points, pharmacies attached to maternity clinics, or pediatric HIV treatment centers. This integration may help some mothers overcome the fear of accidentally disclosing their HIV status by specifically going to an HIV treatment center to receive care. They may additionally reduce the financial burden on mothers, by reducing the number of times a mother has to visit a health facility for herself and her baby.

Lastly, our results accentuate the need for providers to give primary consideration to mothers who experience side-effects from taking ART and address their concerns. A monitoring and follow-up system of women who report ART-related side effects during pregnancy could facilitate rapid assessment of resolution or continuation of patient-reported side effects, allowing for regimen adjustments as needed. We found that there was no follow-up of mothers who related side-effects from taking ART to health workers and once their drugs were finished, they disengaged from care.

The barriers that Ghanaian women face in remaining in HIV care in the postpartum period extend beyond individual motivations and intentions, and in almost every respect are influenced by the backdrop of high poverty rates in this context. However, the other major barrier revealed by our analysis, ART-side effects, could be ameliorated through other initiatives within the healthcare system including counseling or other efforts to reduce these side effects.

Future studies are needed to delineate the retention in care challenges in the postpartum period among women who live in rural areas and also among young mothers (15-24 years). In our study, participants were 22 years or older, and almost all of them were married. In Ghana, unemployment is highest among youth aged 15-24 years [32]. Thus they may face more financial barriers or have lower social support than older, married women. The results of such studies, together with ours, will provide a fuller understanding of the obstacles postpartum women living with HIV face in Ghana in remaining in HIV care for their health.

CONCLUSION

Maternal desire to prevent mother-to-child transmission of HIV and perceived benefit of ART are important factors that can motivate women to stay in HIV care after birth. They can enable mothers to overcome barriers like HIV denial and ART-related side effects. However, they are insufficient in preventing retention loss due to economic and social forces, in particular, stigma and transportation costs. These socio-economic factors are major reasons why retention is more difficult in the postpartum period than during pregnancy among urban women in Ghana. Thus, sustained engagement of postpartum women in HIV care may likely not be achieved without reducing the economic burden of accessing care and tackling HIV-related stigma.

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CHAPTER FOUR: STIGMA TOWARD SMALL BABIES AND THEIR MOTHERS IN GHANA- THE EXPERIENCES OF POSTPARTUM WOMEN LIVING WITH HIV

Figure 4: A word cloud of participants' quotes relating to stigma toward small babies and their mothers

Title: Stigma Toward Small Babies And Their Mothers In Ghana- The Experiences Of Postpartum Women Living With HIV

ABSTRACT

Background: While very low birthweight (<2500g) and premature babies (<37 weeks) are stigmatized in many parts of the world, in sub-Saharan Africa. The intersection of this stigma and living with HIV has not been reported to date.

Methods: We explored stigma related to baby's size. We purposively recruited fifteen postpartum women living with HIV who had given birth to LBW infants from two tertiary hospitals located in Accra, Ghana. In a semi-structured interview, we asked mothers about their understandings of the etiology and impact of LBW, and their social experiences of having a LBW infant in the postnatal period. Data analysis was informed by interpretive phenomenology.

Results: Mothers' evaluation of their babies' smallness was based on the baby size, and not their hospital-recorded birth weight. Their narratives indicate that having a small baby was a source of stigma because of the newborns "undesirable" physical features and people's unfamiliarity with their size. Many of the mother's stories show that they and others characterized small babies as being abnormal or looking "animal-like." This devalued identity, mothers reported, was the basis for several negative stigmatizing behaviors from society toward the mother-baby dyad and also from the mother toward the infant. Key facets of the stigma participants report included initial maternal detachment; reluctance to show the baby to others; experiences of gossip, stares, and expression of shock; and maternal blame. Participants described ways in which mental distress from HIV diagnosis contributed having a small baby and how having a small baby was a reason for not disclosing HIV to partners or relatives.

Conclusion: In Ghana, being born small is an attribute that invites stigma toward the mother-child dyad. HIV-related stigma may intensify negative social interactions as a result of having a small baby. Maternal intention to disclose HIV status to relatives and partners after childbirth may reduce afer having a small baby. The findings support a multi-pronged approach, including sensitization, counseling, and multi-disciplinary health care team to address this stigma and its mental health consequences.

Key words: HIV, premature, low birthweight, stigma, Ghana, maternal blame, qualitative

INTRODUCTION

The experience of stigma is detrimental to mental and physical health [1]. In his influential work, Goffman's (1963) defines stigma as an "attribute that is deeply discrediting" that results in the bearer being "tainted or "discounted." [2,p.3]. Society perceives the stigmatized as "not quite human"[2,p.5] or fully competent. An affiliation with the stigmatized, such as through caregiving, can also confer upon people a courtesy stigma [2]. Individuals who experience courtesy stigma also encounter negative social interactions because they share in the "spoiled identity" of the discredited, though they do not "physically" have the quality that is stigmatizing [2, 3]. Recent views on stigma have included status loss and discrimination as constituents [4].

In non-western countries, some studies suggest that very low birthweight and very preterm birth is associated with stigma [5]. In sub-Saharan Africa, one study conducted in Uganda found that some caregivers of very preterm babies rejected their newborns [6]. In one part of the Middle East, where the discrediting aspect of the stigma is the child's "imperfect" body, some mothers felt ashamed to show their babies to their families and in public and hid their babies[5]. In Asia, negative stereotypes about the infants' future mental ability have been blamed for the stigma toward mothers with small babies [7]. In one Korean survey, 30% of respondents preferred to place such children for adoption than to care for them [8]. These studies imply that social and maternal distancing from the small baby may be a key aspect of this stigma. They also demonstrate that small babies' physical attributes and mental abilities may be held as stereotypes that discredit their abilities.

These interpretations are congruent with Scheper-Hughes anthropological work, *Death Without Weeping*, in northeast Brazil [9]. She theorizes that in regions with high child death expectancy and poverty, a baby's small size is one of the many markers that is used to differentiate infants who will survive and thrive and those who are more likely to die. Children who have elevated susceptibility not to thrive experience delayed or attenuated maternal bonding, and at the extreme, "mortal selective neglect" [9, p.309.] Detachment, she explains, is an element of stigma, functions to minimize grief, and is an active survival strategy in the context of poverty, deprivation, and economic exploitation. Consequently, the community did not stigmatize the mothers for having a small baby, though the babies were stigmatized. These studies suggest that the facets and recipients of the stigma around a baby's size may vary across context.

To date, stigma relating to a baby's size has received less attention in research conducted in sub-Saharan Africa. Most studies have devoted attention to the care[10, 11], risk factors [12, 13], mortality[14, 15], and maternal mental health[16, 17] associated with LBW or preterm babies. In the few studies that describe stigmatizing behaviors [6, 18], stigma was mentioned cursorily and was not a key focus[6]. As a result, the social-cultural context, nature, and response to this stigma have not been well characterized. Given the dearth of research on the lived-experience of families of LBW and preterm infants in sub-Saharan Africa[19], more studies are needed to help us understand this sitgma in the sub-region.

HIV infection, a risk factor for LBW and premature birth[20], disproportionately affects countries in sub-Saharan Africa. About 25.5 million of the 36.7 million people living with HIV reside in the sub-continent [21]. In Ghana, pregnant women living with

HIV have a six times higher odds of giving birth to a LBW infant compared HIV-uninfected women[22].

Living with HIV itself is stigmatized and associated with discrimination[23]. Among people living with HIV, high levels of stigma are correlated with low social support, high depression rates, poorer physical health, mental distress and lower levels of use of health and social services [1]. HIV may add another layer to the experience of stigma associated with small babies by contributing to a more severe stigmatizing experience, including limited social support, discrimination and further self-isolation from others, which have significant impact on mental health. How HIV intersects with stigma toward small babies has not been elucidated. [24] Thus, the objective of this study was to document the lived experiences of HIV-infected mothers with LBW infants in Ghana, by elucidating how they define their babies' condition, the nature of the stigma they experience, and its effect on them [19].

METHODS

Setting

This study was carried out in the Greater Accra Region, the second most populated of the ten administrative regions in Ghana. About 40% of the population in the region belongs to the Akan, 30% to the Ga-Dangme, and 18% to the Ewe ethnic groups[25]. The Greater Accra Region has the highest HIV prevalence among women of reproductive age (15-49 years), at 3.8%. In Ghana overall, the HIV prevalence is 2.0% and among women of reproductive age, it is 2.8 % [26]. The mother-to-child transmission rate of HIV by the end of breastfeeding cessation is 18% [27]. Based on the 2014 Demographic Health

Survey, about 5% and 11% of mothers in Ghana perceive their babies size at birth to be very small and small, respectively [26].

The study sites were two tertiary hospitals, Korle Bu Teaching Hospital and Ridge Regional Hospital, located in the city of Accra, Ghana's capital. Twenty-three thousand deliveries a year occur at these two hospitals. Based on facility records for 2015, the prevalence of LBW among mothers living with HIV in the two facilities is 8%.

Study Participants, Sampling, and Recruitment

We draw data from interviews with 15 postpartum women living with HIV with LBW infants. Postpartum women were included in the study if they were living with HIV, gave birth at or were receiving HIV treatment at the two hospitals, were 18 years or older, and had an infant under one year of age. Participants were purposively sampled based on hospital-recorded weight at birth of <2500g. Given that prior studies have primarily relied on accounts of women whose babies were admitted to the neonatal intensive care unit (NICU),[5, 7] we sought to also get the views of mothers of babies who were not in the NICU. Of the 15 participants, eight women had infants that had been admitted to the NICU and seven did not.

We recruited mothers via health workers at the maternity, adult and pediatric HIV treatment centers, and the NICU. In addition, the two facilities keep a record of mothers living with HIV who gave birth there, their babies' birth weight, and date of birth. With permission from the medical directors of the hospitals, a health worker at each site telephoned the mothers and passed on the contact information of those who were interested in participating to the data collection team. A female member of the team

contacted all the interested participants via phone and provided more information about the study. She was a former HIV counselor and had received an in-person training on ethics and confidentiality through an FHI360 project before the study.

Apart from data from participants, we also draw from informal conversations with three clinical staff members at the NICUs at both hospitals and field notes from a church service that the first author attended when a man spoke about the physical disability of his son. These sources provided the opportunity for triangulating the reports of the participating postpartum women.

Data collection lasted three months, from February through April 2016. The first author and two research assistants (one male and one female) conducted semi-structured interviews with study participants. The first author, a social and behavioral scientist, trained the research assistants on interview techniques and research ethics during a week-long training that included role playing.

Thirteen of the interviews were conducted in Twi, and two were in Ga. Interviews were conducted either at the hospital or in participants' homes and ranged from 20 minutes to more than an hour. After the interview, each participant received the equivalent of $3 and one pack of a baby diaper. The interviews elicited detailed stories about caregivers' thoughts and feelings after birth, experiences with caring for their babies, situations or context that affected their experiences, and views on children that are born small in size.

All the interviews were audio-recorded, except those of four participants who declined voice recordings. In these cases, handwritten notes were taken and transcribed

immediately following the interview. All the audio-recorded interviews were transcribed verbatim.

Participants also completed a structured questionnaire including socio-demographic characteristics, HIV history, and birth outcomes. Data on birthweight were extracted from pharmacy records. Field notes were taking during the data collection period including observations during visits to the NICU and informal conversations with the three NICU staff.

Analysis

We began data analysis during data collection, which included listening to the audio recordings and reading each of the transcripts to get a global sense of the text.[28] Debriefing by the interviewer to the research team was also carried out after each interview to discuss key experiences of each participant. After data collection, the first author developed a codebook from coding four transcripts. The codebook was further refined through additional coding and systematically applied to the remainder of the interviews. The codes were then used to identify sections of each transcript that related to small babies.

The sections were analyzed interpretively, drawing from Smith's work on interpretive phenomenology[29]. Smith advocates for attention to metaphors and temporal construction of narratives to guide interpretation of participants' stories. Hence, for each of the selected sections in the transcript, the text proceeding and following it was also examined to construct the temporal sequence of participants' narratives. A key focus was on

participants' use of local terminologies, analogies and to the cultural context where their experiences occurred.

The selected sections were organized and clustered into themes based on their similarity in meaning. The relations between themes was determined through contextualization (i.e. attending to the sequence and narrative moments when certain themes appeared) [29]. A conceptual model was produced to illustrate the relationship between themes. Memos were kept throughout the analysis. All analysis was done using Atlas.ti.version 7 [30].

Ethics

Three ethical review boards approved this study. They were the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No. 6651), the Ethical and Protocol Review Boards of the Ghana Health Services (ID: Ms-Et/M.2-P4.1/2015-2016) and the University of Ghana Medical School (ID: GHS-ERC 16/09/15). All participants provided a written informed consent before the interview proceeded.

RESULTS

A total of 15 women were interviewed. All but one of the participants lived with a partner. A little over half of had completed primary school. A quarter belonged to the Akan ethnic group and one-third to the Ga-Damgbe group. The mean number of children of participants was two [range, 1-4 children]. Participants' age ranged from 26 years to 44 years; the mean was 36 years. The average number of years living with HIV since

diagnosis was four years [range, 0.5 to 16 years]. All the women were on antiretroviral therapy.

The mean birth weight of the infants was 1.88kg [range, 1kg-2.48kg]. Eleven out of the 15 mothers with LBW children evaluated their babies' birth weight as small (N=6) or very small (N=5). The mean age of the infants was six months and ranged from 5 days to 12 months.

We present results on maternal perception of infant size and the components that constituted stigma toward small babies.

How babies are ascribed a small status

Participants' assessment of their babies' smallness did not focus on their weight, but their size. Mothers commonly used these three phrases to describe the size of their babies at birth: 1) "*Na wosa paa*" (the child was really small), 2) "*Na wo ye ketewoa bi" (*the child was tiny*),* and 3) *Na wo ye kete kete (*the child was tiny tiny)." The local words "w*o sa"* and "*kete,"* or its variation *"ketewoa,"* are used to indicate a small amount or proportion of something. Sometimes, participants emphasized the smallness of their babies by describing how difficult it was to care for them: "*She was small such that I did not know how to carry her*" or how fragile they were: *"if you do not hold him carefully, you might harm him by breaking him"*

Beyond these phrases and descriptions, we asked participants what local terms are used to describe children who are born small, and many did not know any. The most common label offered was the English word "premature." Other names included *"aketew"* (the tiny one), "*obumpa*" (sarcastically, the one who is heavy enough to break a

bed),"*"kukuba"* (the baby born small enough to fit into a pot) and *Asram kotrɛ*. *Asram* is a local umbrella term for a range of symptoms that affect infants [31, 32]. *Kotrɛ,*the local Twi name for a lizard, is used to connote that the baby's size is as small as a lizard.

Designation as small in size did not always occur at the time of birth. Some participants indicated that their babies were born "normal" or "big" but became small later on because they lost weight.

Features of stigma toward small babies and their mothers

The majority of the participants' narratives indicate that stigma toward small babies and their mothers was closely connected to the babies' 'undesirable' physical features and people's unfamiliarity with the baby's size. These two factors led to a devalued identity of the babies (see description below) as human beings, which, in turn, contributed to the main negative experiences mothers reported: maternal detachment, reluctance to show the baby to others (extended family, neighbors and friends), emotional and mental distress, and negative social reactions (gossip, unwanted stares, expressions of shock, and maternal blame). In Fig.1, we illustrate the dimensions of the stigma toward small babies. We group the key themes under perceptions of the size of the infant, maternal reactions, and societal reactions. We organize the results around these categorization.

Devalued identity of the newborn

The stories of mothers indicate that small babies' humanness are devalued. Several made comparisons of the baby to an animal (commonly lizard, mouse, frog), and

others emphasized their physical appearance looked ‘abnormal’ compared to other children. A mother whose baby weighed 1.0 kg described:

> *"I said no that could not be my baby and that it was an animal and I cannot believe that I have given birth to such a baby. There were some of the mothers sitting outside, and they were talking about me. I told the nurse that this animal was not my baby because when I give birth, my babies are beautiful -- and why is this one like this?*

Another mother whose baby weighed 2.3kg at birth and his weight deteriorated to 1.8kg described:

> *He was not normal. Not normal…there are some children when you give birth to them, you know that they are normal; they look normal. But this one, he didn’t look right… If you saw the face, my brother, stop, you would have been scared; you would have thought that it was an animal.*

The use of the pronoun it is not unique to small babies. It is common in Ghana for a newborn to be referred to as “it” rather than him or her when the baby has not been given a name. Interesting here is the participant’s use of “it” to refer to the baby though she had already given him a name.

The physical attributes that made mothers describe their babies as 'animals' or 'not normal' varied, but commonly they referenced: 1) how their skin looked, particularly its turgor and color, and 2) how small they were and 3) the amount of hair they had on their head. One mother described her son as having: *"nothing in him...you only saw the bones. His skin was like that of an old lady … it looked wrinkled."* Another remarked: "*the knee and the hands had shrunk. The baby was also very white."* Yet, another participant recalled: *"the baby was so small and tiny, and when you saw the hair, it was terrible. The one besides me was small like this [my baby], and I asked whether this one too was a baby."*

Participants' accounts of how some individuals reacted upon seeing their babies also reflected the devalued identity. They echoed Goffman's observation that "the person with a stigma" is viewed as "not quite human"[2,p.5]. In the quote below, a mother's sister-in-law questioned whether her baby was a normal child. She focused on the baby's physical features and commented on how they differed from other children in their family:

> *When she [my sister-in-law] came to see my child, she asked, "What kind of a child have you given birth to? In our family, we do not give birth to children that look this small…What kind of child is this with such skinny legs, hands, and toes?"… She followed me to the hospital for us to weigh the child…She asked the doctor if the child was not suffering from a disease… As for having this child, it made living hard for me.*

As a result of child's devalued identity, both the mother and child were recipients of stigmatizing behaviors from others.

Gossips, unwelcomed stares, expressions of shock and maternal blame

Some mothers reported that the attributes of their baby resulted in negative social interactions toward them and the child. These reactions represented a spectrum, from an expressions of surprise to overt restriction of social support, a form of discrimination.

The narratives of the mothers suggest that their experience was a form of "courtesy stigma."[2, p.30] That is, even though the mother did not share the characteristics of the baby, their connection to the child made them share in the baby's devalued identity. The quote above, and others like the one below, suggest that society viewed the mother as responsible for the birth of such a small child. In essence, the mother, by producing the offspring shared a similar identity and are, in many ways, inseparable to the eyes of others.

> *She [my sister] asked me, 'What small child have you brought to this house? …You are always pointing out the flaws in others' children and insulting them, have you seen what you have given birth to? Is this what you have given birth to?'… I told her to leave me alone"*

Many of the mothers recalled that people's first response upon seeing their child indicated "surprise," "shock," or "being afraid" of the baby. "*As for the 'Fantes' (an Akan tribe) they were much surprised at the kind of child I have given birth to*," said one mother. Another mother reported: "*So I couldn't even bring the baby out. I couldn't! If someone saw it, the person will think 'to what kind of "thing" has this woman given birth'…"* She further remarked about women at the postnatal clinic: *"Oh! They also stare. It's not different. They really stare at you!*" Another talked about feeling blamed:

> *At first, when I went [postnatal clinic], they [nurses] blamed me that I was not giving the child breast milk that is why the baby looked the way it did.*

One participant described severe mistreatment from others, which may have been exacerbated by living in a compound house (with several non-family members) and not waiting for the baby to gain sufficient weight before bringing her out publicly. She described that her neighbors' possible knowledge of her HIV status worsened their reactions toward her. Her case demonstrates the interplay between HIV disclosure on stigma toward small babies and the mother, and an experience of discrimination.

First, she reported her neighbors labeled her as a witch for having a tiny baby, a severe social charge. As Adinkrah points out, being labeled a witch in Ghana is a "defamation of character" and "loss of reputation" [33,p.347] it results in loss of status and honor and can be a significant source of mental distress[33]. Society views witches as the "embodiment of evil"[33,p.336] .

The child was very tiny, and so they were a bit scared. They said the child was too small and that I should take her to my mum … The child too could cry very loudly, so when I bathed her, people will approach, and when they saw the child, they realized it is just some tiny baby. They thought I was a witch.

She further reported that her neighbors gossiped about her, pressured her to leave her home to stay with her mother, and withdrew social support. As a common practice in Ghana, especially for a first-time mother, the woman's relative or an experienced woman bathes the newborn until mother learns how or is strong enough to do it by herself. This support can last up to a month [34]. This participant was a first-time mother, and the woman who assisted her with the child's bathing stopped coming after a few days. In essence, she lost a social privilege mothers typically enjoy. The participant related that her HIV status might have been the reason for these negative interactions.

Because the child was small, they used to whisper among themselves, and when they saw me coming, they stopped. They might have heard that I had gotten this illness [HIV] … The person who was supposed to bathe the baby later stopped coming.

Among the study participants, HIV and stigma toward small babies intersected at the level of maternal blame, but rarely through overt mistreatment like this participant experienced.

It is important to emphasize that some of the participants did not report experiencing negative treatment from individuals within their family and social circles. In many of these cases, participants shared that their family members or friends had seen a small baby before. They further indicated that such family members had more positive views about the baby, and they encouraged them.

> *Most of them had seen premature babies before and were positive about their outcome [that they will survive]. Some said that she would be fat later; others also said that those are the type of kids who become brilliant, and so I should not worry about it since she will put on weight after a while.*

Initial maternal detachment from the baby

Some mothers described detachment from the baby due to this devalued identity. A few of the mothers' narratives reflected a weak emotional bond to or detachment from the child. These reactions suggest that some of the stigma was directed from the caregiver to the baby.

A wide range of behaviors reflected this detachment, including reluctance to embrace the child and separation from the baby. One mother upon seeing her baby recalled not accepting the baby as hers: "*I told them to look for my baby for me. Then*

they said that they would look for my baby for me, so I should go and rest." She did not want to take care of the baby and separated from her baby for a while, who was receiving care from her sister. She was also significantly distressed then and had to see a psychologist. She resumed childcare two months after, when the baby had gained enough weight.

Supporting this, informal conversations with neonatal intensive care unit (NICU) nurses and observations of the study staff reinforced the idea of this maternal detachment. NICU nurses explained that some mothers left their babies at the NICU after birth, only to return when the children have gained sufficient weight. This was corroborated during one of our visits to the neonatal intensive care unit to recruit participants. One mother had left her baby at Ridge Hospital and had not visited for two weeks. According to the nurses, she wanted them to call her if the baby survived and gained enough weight. In a religious service the first author also attended during data collection, a man also told a story of how he and his wife left their very preterm baby to be cared for by his mother-in-law because it looked like an "animal" and they did not also know how to care for him. They also resumed care for their son when he had gained adequate weight. These experiences suggest that the distancing of parents to their small babies often attenuated as the baby gained sufficient weight.

Reluctance to show the baby to others

One common finding was that almost all mothers with small babies in the sample demonstrated a reluctance to show the baby to others. Mothers reported using various strategies to prevent others from seeing their infants because of their size and appearance.

Some of the strategies included giving excuses to prevent visits, not telling people that they had given birth, hiding their babies before a visitation, and delaying "outdooring." Among our participants, these strategies were often employed in the first three months and commonly used in three main social scenarios: 1) visitations, 2) outdooring, and 3) transportation of the newborn.

As mothers' accounts of these scenarios suggested, the reluctance to show the baby to others created isolation, but it also had positive functions. For a few, it served as a coping mechanism against social gossip and unwelcomed stares. For many, it allowed them to buy time to present a better image of their child to the public. In essence, reluctance to show the baby allowed caregivers to manage what Goffman's call a "spoiled identity."[2]

Relatedly, the ability of mothers's to manage this spoiled identity suggest that without others' knowledge of their child, their social identities were not discredited; which echoes this idea of "courtesy stigma".

Adjah explains that for most ethnic groups in Ghana (Ga, Ewe, and Akan, for example) a newborn is not given a name until about the eighth day after birth [35]. Before then, families hide the baby from public view because of a belief that the baby is still attached to the spirit world and could decide to return (i.e. die). Visits to see the baby, particularly by non-family members, are typically restricted before the naming of the child. On the eighth day, the baby is meant to stay in this world; thus, his/her family hosts a celebratory event called an outdooring ceremony. The family introduces the newborn to the public and announces the child's name [35]. Without the symbolism of a name, Ansu-Kyeremeh asserts that the "child's humanness and identity is [not] confirmed" [36,p.24].

Among the Ga's, Abbary reports that a newborn's mother and father do not receive a social identity as parents without the naming ceremony[37]. The death of the baby, particularly before the 8th day, denies them that identity. Thus the naming ceremony is important for the child and parents, but more so, for the baby[37].

In our study, the majority of participants with small babies reported regulating when people saw or could visit their newborn. Many relied on the cultural norms around visitation and outdooring to provide socially acceptable reasons for preventing a visit. Some simply did not allow others to visit and one mother described hiding her baby when someone tried to visit her.

> *Well, people did not come to my house during the first week. The baby was too small, and I wouldn't want people to see the baby. It was after a week that I started to let people come. At that time she had gained enough weight.*

> *One day, we were outside of the room to get some fresh air, and I didn't know that she [a family friend] was coming to visit me. When she eventually made it to the house, I quickly took the baby inside. I told her that she could not visit because we had not officially "outdoored" the baby... Then she got really mad.*

In addition, a few of the mothers with small babies described delaying the outdooring of their babies until they felt their newborn's weight improved. They did not

want others to see their children's size and physical appearance. As reported, the delay in outdooring allowed several caregivers to present their children when their appearance improved.

> *I did not let people come in [to visit], except for those to whom I am close. They are the ones who will come to see the welfare of the baby. Other than that, it was until we did the outdooring that we made our neighbors see the baby. We were able to bring him out because he looked much better than when he was born. If he was still looking as he was when he was born, I do not think we would have done that. We took him out… around 29th of February [two months after the birth]*.

The third circumstance where maternal distancing of the baby from others occurred was when participants were transporting a small baby from their home to a public space. Mothers generally tried to hide the baby from public view during transport. For example, some mothers related taking a taxi for this reason, instead of the local bus which tended to have more people. However, some caregivers, for economic reasons, were forced to take public transportation. In such a circumstance, one mother described laughingly, *"I covered it. I covered it really well.*" She related only exposing the baby's nose for him breathe and holding the baby close to her chest to prevent people from noticing the baby.

Emotional and mental distress

As a result of their newborns' size and reactions from others, several of the mothers reported experiencing emotional and psychological distress. Relevant to this discourse are the local phrases that are part of idioms of patients who are diagnosed with depression in Ghana. Ohene and Addom (2014), explain that there is no single word in any Ghanaian language for depression[38]. Ghanaians who present with clinical depression commonly use local phrases that translate to "thinking too much."[38] The expression connotes obsessive remuneration[38]. In the Akan language, the root word for this phrase is *dwen (to think)* and for emphasis, *adwen adwen or dwen dwen*.

Participants' accounts indicate that some felt discouraged and others experienced depressive- related symptoms, such as self-isolation, prolonged sadness, crying all the time, and *adwen adwen*. The latter two symptoms were the most reported. One source of these difficulties were the reactions or remarks of others. One participant talked about her discouragement and crying all the time:

> *I was there with my husband's sister... She rather used to encourage me that I should not mind anyone [that is, care about what people said] since the child will be fine. But the members of the house used to make me feel discouraged.*

> *I used to cry when I was alone with my child. I could look at her and cry. I would ask myself, "What kind of evil sickness*

> *[i.e HIV] have I gone in for that this strange thing [i.e being small] has befallen my child?" After crying several times, I would comfort myself and say that nothing is impossible with God, and because I have been on these drugs [ART], God can do it.*

Some of the maternal blame was self-generated, and at times, pinned on maternal HIV infection. Maternal self-blame was an area where HIV, having a small baby, and psychological difficulties intertwined. Some mothers attributed their babies' condition to poor health or nutrition, but for others, it was because of the *adwen adwen* during pregnancy from being diagnosed with HIV. Some participants linked the resulting *adwen adwen* to inability to eat, which, in turn, caused them to have a small baby. For a few, they thought that a combination of HIV, health, and nutrition was at play. One mother explained how her diagnosis caused her not to eat and *adwen adwen,* and their joint effect on the baby's size:

> *It was during my pregnancy that I was diagnosed with this condition, which affected me greatly. It caused me not to eat, and it made me 'dwen dwen' too. I think my eating habit and the 'adwen dwen' had an impact on the baby [being born small].*

In most cases, a negative HIV test result of the child exonerated some of the mothers' emotional and mental distress. The narrative of the participant below affirms this finding. Her story also painted a vivid picture of the intersection of HIV and having a small baby. It reiterated findings around the non-human attributes associated with the small baby:

> *I have given birth before; this is my second child. The first born was very big, but for this baby, when I noticed that I had acquired this illness, I cried and lost weight…When I gave birth to her, like a lizard's child, she was all white, her skin was very pale, and she was very tiny. I did not know her skin color could even turn black. You could see and count the ribs, like how the offspring of an animal looks like when they are born. Her eyes were very wide open; she did not look like a newly born baby when you looked at her eyes. I fell ill [with HIV] when I was pregnant with her and was given the drug [ART]. I was sick for a month. I could not eat and drink; I had sores in my mouth. Even, to drink a little soup, they had to put a straw in it for me to suck. I was terrified and thought maybe it was the sickness [HIV] that I had that had a negative effect on the child. I was scared she might have the disease [HIV], so when we came, and her blood was tested, and it was negative, I was glad.*

Some participants related that having a small baby was a reason for not disclosing their HIV status to either their partners or others. One reason was that some thought the baby might be infected: *"Before I did the first test on him to know his [HIV] status, when I saw him first, I thought the way he was small, he might be infected."* Several mothers seemed aware that HIV-disclosure to relative or partner would result in being blamed for their babies' condition. Supporting this idea, we found that the mothers who had small babies who had not disclosed their HIV status before giving birth did not do so after birth. One example is this mother who did not tell her family and partner about her HIV status in the context of having a small child.

> *The midwife came asking me if my family were aware of my status and I told her no. Hm, this issue [HIV disclosure], it's something I have kept in my head. Because of this case [having a small baby], I couldn't tell them [that I am infected with HIV] and because I could not tell them why, when I gave birth to her, in fact, I could cry.*

> *People wondered [about the size of the child]… The child was too small and no one including my husband had any idea what sickness [HIV] I suffered from that made me give birth to such a small child.*

We found that maternal self-blame was minimal when a mother or her partner's previous babies were born small. Some were also accepting that not all babies are born big, so they need not blame themselves.

DISCUSSION

Our results suggest that being born small is stigmatizing characteristic for infants in Ghana. In our study, we found that small babies were devalued because of their physical appearance. They were reduced from being a "baby" and "normal human being" to being an "animal" or "abnormal." Social devaluation of an identity is key experience of the stigmatized.

Our designation of small baby as a stigmatizing condition encompasses status loss and discrimination, which is consistent with components of stigma included in more recent conceptualizations[4]. In our study, we found that some mothers delayed the outdooring of small babies, a potential response to a loss of status associated with baby size. In several ethnic groups in Ghana[37], children, especially newborns less than eight days old, occupy the lowest social status. Newborns are not "recognized" as part of the larger extended family or clan until they are named [36, 37]. Without a naming or outdooring ceremony, the newborn is "without social identity, an amoral, non-person" [37, p.367] and does not occupy a status within the extended family or clan [35, 37]. Thus, a delay in outdooring of the small newborns is a delay in recognition of their social status including the privileges given to other newborns such as interaction with other community members, receipt of gifts, and an identity (conferred during or after the outdooring ceremony)[35].

The attribute we report that makes small babies socially stigmatized in Ghana seems different from in other settings. For example, in Korea, the discredit stems from stereotypes about the children's potential mental disability[7]. In our study, we did not find a prominent perceived association between a baby's size and future mental disabilities among our participants. In fact, mothers' narratives show that one way others encouraged them was by highlighting how such children will become intelligent, healthy, and productive in the future if they receive good nurturing. The view in Ghana about the child's bright future prospect contrasts that in Korea. One possible explanation may be that the survival chances of very LBW and very premature babies in the two countries are different [39]. In her anthropological work, Scheper-Hughes theorizes that in places with very high mortality in children, such as in Ghana, social stigmatization around a baby's size is organized around survival goals[9]. Social attitudes toward them change from negative to positive once such children survive past periods deemed locally as high risk of death or show signs that they will thrive (such as gaining weight and being active)[9]. This interpretation is consistent with our finding that several of the components of the stigma, maternal detachment and reluctance to show the baby, for example, attenuate with the baby's weight gain.

Our results that participants were reluctant to show their babies to others is similar to findings from other studies. We found that some mothers lied about giving birth, hid their babies from others, and prevented visitation altogether to avoid stigma. In one study in Zimbabwe, some mothers with small babies who practiced kangaroo mother care had to lie to others that they had not given birth[18]. Research conducted in the Middle East and Asia showed that some mothers felt ashamed to show the newborn to their extended

family, other mothers, or in public.[5] Consequently, they hid their children, particularly those who had additional physical abnormalities.[5] Together, these studies indicate that reluctance to show the baby is a vital part of the stigmatizing experience relating to a baby's size.

We contribute to a deeper understanding of this theme in many ways. One, we are the first to show how caregivers use cultural norms around newborns, such as visitation and naming, as instruments to regulate visits and avert stigma in Ghana. Further, we also show that caregivers' experiences are a reflection of courtesy stigma. We demonstrate that reluctance to show the baby is one way caregivers present a "normal" narrative about themselves to others. Their social identities are threatened if others see or know about the child; their affiliation with the child is what results in their "spoiled identity." Reluctance to show the baby is one way of managing or eliminating that discredited identity.

Our finding that small baby size contributes to maternal detachment extends findings from other studies. We found that maternal detachment was a spectrum, from difficulty with emotional bonding to separation from the child. In a systematic review of kangaroo mother care for small babies, stigma was associated with difficulties with maternal bonding with tiny babies [40]. In Uganda, some mothers with very preterm babies reported that they would have preferred to have had miscarriage rather than have their babies [6]. In a qualitative study in Iran, some mothers related telling their partners they did not want their children anymore. Others felt ashamed to show the newborn to their extended family or in public [5]. We show that in the sub-Saharan context of Ghana, the detachment can extend beyond attitudes about not wanting to keep the baby into prolonged separation, such as leaving the child at the NICU. We suggest that part of the

separation may be the result of the devalued identity of the newborn and is a form of stigma toward the child.

While this interpretation is consistent with anthropological work in northeastern Brazil, for example, the work of others suggest that this stigmatizing behavior may have survival or coping functions for the caregiver[9, 41]. In China, researchers compared the experiences of immigrant and native Hong Kong mothers receiving care for the babies at the NICU. They found that some immigrant mothers distanced themselves from their newborn, in this case, from visiting their babies in the NICU, because they wanted a temporary relief from the stress of childcare. They had minimal or no social support and were economically disadvantaged. The women saw the avoidance psychologically beneficial and necessary[41]. Distancing or maternal detachment may thus be a symptom of socio-economic disempowerment or response to mental distress, a theory consistent with Schepes-Hughes thoughts on "mortal selective neglect." [9, p.309]

Our study extends this finding and adds that maternal HIV infection is a source of self-blame for giving birth to a small baby. Maternal self-blame is a common theme that emerges from studies with caregivers of small babies generally[16, 42]. Gold et al. (2013) surveyed mothers with sick newborns admitted to a NICU in Ghana, which included LBW infants. About 27% and 10% of the women with sick neonates reported moderate and severe depression, respectively and one-third reported maternal blame [16]. Some of our participants attributed having a small child to depressive-related symptoms that followed their HIV diagnosis. We found that to avoid blame from others for having a little baby, some mothers did not disclose their HIV status to their partner or other relatives. While we did expect that mothers living with HIV will not disclose their HIV

for several reasons, we did not anticipate that having a small baby will be an additional reason for non-disclosure.

There are several nuances to the stigma toward small babies and their mothers that warrant discussion. First, the extent of the stigma varied, with some mothers not experiencing stigma towards their babies or all the facets of the stigma. Given that we found maternal detachment and reluctance to show the new attenuated after the baby gained weight, it is likely to be stigma may be most prominent in the first three months after birth. We found that newborn weight at birth recorded at the hospital did not appear to closely correlate with mothers' evaluations of their babies' size or experience of stigma.

Limitations and strengths

Our study has limitations. Our focus on stigma draws attention only to the negative facets of caring for small babies. Such emphasis minimizes the resilience, love, and agency mothers in our study displayed in addressing the challenging needs of their newborns. Our participants also included only women living in an urban area. While we do not think that these experiences are unique to women in urban areas, we anticipate that the intensity and components of the stigma could vary across context, given differences in living arrangements, socio-economic status, and perceptions of small babies. It is also possible that stigma is exacerbated in more rural communities, where families may live in compounds and mothers may have less privacy during the postpartum period.

Despite these limitations, our study has some strengths. Our research is one of the few that has examined newborn size as a stigmatized condition in sub-Saharan Africa.

We also bring into light some of the intersection between HIV and experience of stigma toward small babies.

Practice Implications

Implications for public health and clinical practice include the critical need for the stigma toward small babies and their mothers to be tackled. In this endeavor, public health practitioners should increase public awareness about small newborns and promote positive associations with them. Such interventions could minimize people's unfamiliarity with their physical features, which partly contributes to the stigma. As mothers' accounts showed, people who had seen small babies thrived did not stigmatize them and were a source of encouragement. Antenatal clinics and mass media outlets can be conduits for sensitization. Practitioners can nurture positive associations through the use of images of small babies who have thrived or stories of mothers whose children have flourished.

Furthermore, before discharge from the NICU, health workers should sensitize mothers of small babies of what to expect and how to address the stigma-related challenges. This need, together with the depressive-related symptoms these women faced, calls for mental health practitioners to be part of the NICU team in Ghana. Health workers could also harness the experience of mothers who have lived through this stigma to give social support to newer mothers with small newborns. Health workers could incorporate them into a support group facilitated by a trained professional or train them to provide informal counseling through the phone or in-person.

Lastly, but not the least, these efforts should be coupled with interventions that further weight gain in small babies, such as through breastfeeding or nurturing care. This recommendation is critical as many of the components of the stigma mothers reported resolved through the baby gaining weight.

In the future, more research is needed to determine the transferability of our findings across different parts of Ghana. These studies should include rural women and also family relatives of mothers with small babies to give a holistic picture of women's experiences.

CONCLUSION

Being born small at birth is a cause of stigma in Ghana. Our findings suggest that, in the short-term, stigma may impact maternal attachment and contribute to mental health problems in caregivers. The findings support a multi-pronged approach to address this issue, including sensitization, counseling, and a multi-disciplinary health care team to address the stigma and its consequences.

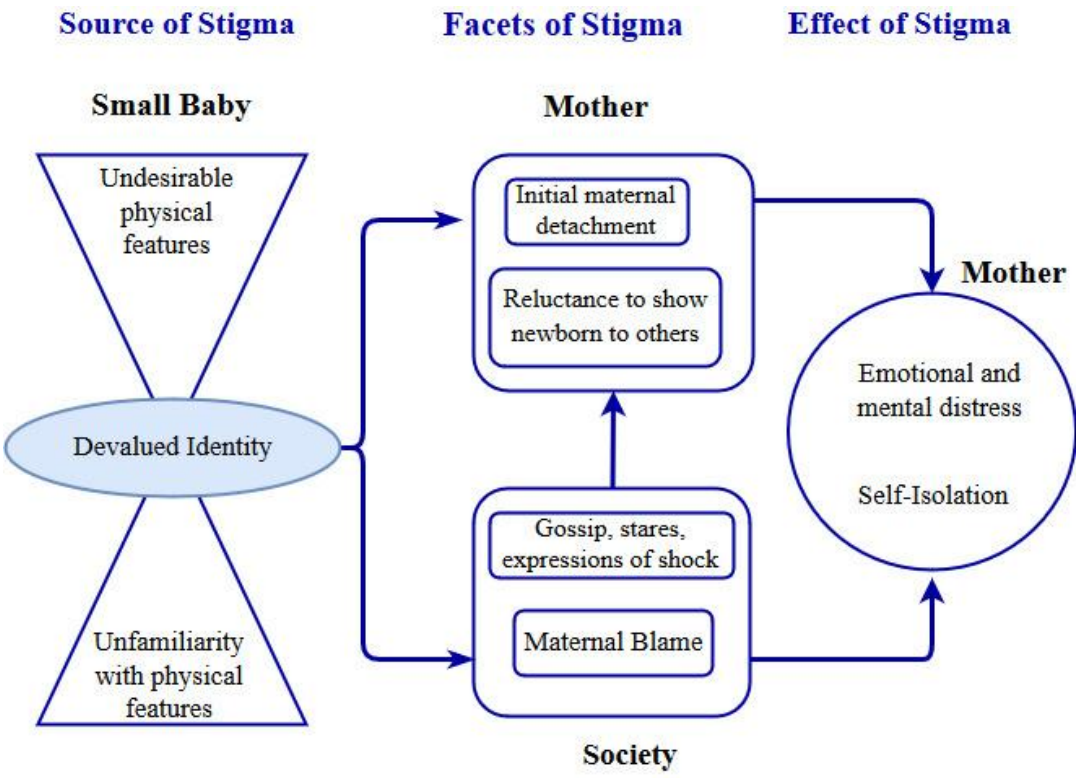

Figure 5: Visual representation of stigma toward small babies and their mothers in Ghana as described by participants

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CHAPTER FIVE: "TIME BEATS ME": LOW BIRTHWEIGHT AND MATERNAL ENGAGEMENT IN HIV CARE IN GHANA

Figure 6: A world cloud of participants' quotes relating to LBW and maternal engagement in HIV care

Title: "Time beats me": Low birthweight and maternal engagement in HIV care in Ghana

ABSTRACT

Background: HIV is associated with an increased risk of having a low birthweight (LBW) baby (<2500g). Care for LBW infants has been shown to contribute to psychological difficulties, such as depression, which is associated with poor antiretroviral therapy (ART) adherence. In some countries, including Ghana, LBW infants are stigmatized which may create challenges for retention in HIV care. Already, rates of ART adherence and retention in HIV care among postpartum women are low. We explored how caring for LBW infants may affect ART adherence and retention in HIV care during the postpartum period.

Methods: We conducted thirty in-depth interviews with postpartum women living with HIV in Accra, Ghana: 15 with LBW infants and 15 with normal birthweight (NBW) infants. Women were purposively selected from two tertiary hospitals that provided Option B-plus to prevent mother-to-child-transmission. We analyzed data inductively using an approach informed by grounded theory.

Results: Compared to those with NBW infants, mothers with LBW infants were more likely to link caring for their newborns to caregiver burden, prolonged hospital stays, and stigma. Based on participants' accounts, caregiver burden and prolonged hospital stays directly contributed to incomplete ART adherence and missed clinical appointments. Mothers' narratives suggest that stigma often led to challenges for keeping clinical appointments for HIV care by affecting the mode and cost of transportation. For a minority of women, caring for LBW infants created opportunities for re-engagement in

HIV care and motivated them to adhere to ART.

Conclusion: Mothers living with HIV with LBW infants need social support to reduce caregiver burden. This reduction will, in turn, help them adhere to ART and keep clinical appointments. Our qualitative study suggests that LBW may be associated with lower maternal engagement in HIV care in Ghana. Quantitative-based studies are needed to test this potential relation.

Keywords: Low birthweight, retention, adherence, postpartum, HIV, antiretroviral therapy, Ghana, qualitative

INTRODUCTION

Retention in HIV care has been shown across multiple studies in and outside of sub-Saharan Africa to be low in the postpartum period, with more than 1 in 3 not retained in care six months after giving birth [1-6]. Postpartum women also have lower antiretroviral therapy (ART) adherence rates (57%) than pregnant women (75%) [7]. Both retention in HIV care and ART adherence (referred to as engagement in HIV care henceforth) are associated with increased risk of HIV transmission, mortality, and HIV-related morbidity [8].

Reasons for low engagement in HIV care in the postpartum year are insufficiently understood. Demands of caring for a newborn, prioritization of child needs, and limited social support for child care may be among the underlying factors [9-11]. Newborn health status may also influence postpartum engagement in HIV care. For example, people caring for relatives with serious health conditions are less likely to use preventive health services compared with those without these responsibilities [12], as they often prioritize the care for their sick family members (e.g. infants, spouses) over their own health (e.g. attending medical facilities themselves) [13].

Caregivers of children with significant health problems are also more likely to experience caregiver burden—a physical, emotional, and/or financial stress that results from caregiving [13]. Caregiver burden has been linked to low use of preventive health services and psychological difficulties [13]. Among caregivers living with HIV, psychological difficulties are associated with ART non-adherence [14].

A population that faces significant caregiver burden and psychological difficulties are mothers with LBW infants, in particular, those with very LBW babies [15, 16]. A recent

meta-analysis of cohort studies showed that in sub-Saharan Africa, the odds of giving birth to a LBW baby are about two times higher among woming living with HIV compared to those who are uninifected [17]. In some countries, the prevalence of LBW babies among women living with HIV is as high as 15-20% [18-20]. These high rates, coupled with the caregiver burden and psychological difficulties, underscore the need to explore how caring for LBW infants may affect mothers' engagement in HIV care. Moreover, women with LBW infants in some low- and middle- income countries (LMIC) face social stigmatization [21], which may also increase the risk of depression and social isolation and further compromise engagement in care [22].

Recent reports have advocated for a need to strengthen understanding of the societal and interpersonal factors that influence women's engagement in HIV care during the postpartum period [11, 23]. These insights could facilitate the design of more effective, crosscutting interventions to increase engagement and ultimately improve HIV control and treatment. In response, we explored how newborn characteristics may be barriers or facilitators to engagement in HIV care among postpartum women living with HIV in Ghana.

METHODS

Setting

This study was conducted in Ghana, which has a national and pregnant women-specific HIV prevalence estimates of 2.0% and 2.8%, respectively [24]. We recruited women from two large referral hospitals located in Accra, the capital city of Ghana: Korle Bu Teaching Hospital (Korle Bu) and Ridge Regional Hospital (Ridge). Accra is in

the Greater Accra Region, which has an HIV prevalence of 3.8%, the third highest regional rate in the country [24].

Based on hospital records, the prevalence of LBW among women living with HIV who gave birth at these hospitals in 2015 was 8%. Each hospital has a neonatal intensive care unit (NICU) where LBW babies who need intensive care are admitted. The two facilities follow World Health Organization guidelines for Option B-plus for the prevention of mother-to-child transmission: providing lifelong ART to women diagnosed with HIV, irrespective of CD4 cell counts [25]. At both hospitals, mothers receive postnatal care and HIV treatment in separate units. Within the postpartum year, mothers are typically expected to make at least 12 visits for herself and her newborn. Four visits are needed to collect her ART, two visits to receive postnatal care for the mother-baby dyad, and three visits to get their infants tested for HIV with three separate visits to review these testing results.

Study Participants, Sampling, and Recruitment

Participants included 30 postpartum women living with HIV who had delivered at the study hospitals. The eligibility criteria were as follows: had an infant one year of age or younger, living with HIV, gave birth at or was receiving HIV treatment at the two hospitals, and was 18 years or older. Participants were purposively sampled based on hospital-recorded weight at birth and whether or not they were previously admitted to a NICU.

We recruited mothers who were receiving care through the 1) maternity clinics, 2) NICUs, and 3) adult and pediatric HIV treatment centers via health workers. Also, the

health facilities had the contact information of women living with HIV who had delivered at the facility. With permission from the head of each facility, a health worker at each site telephoned women living with HIV who had delivered at the hospital within 12 months prior to the study, and if they expressed interest in participating in the study, the health worker shared their contact information with the study team. One of the study team members, a female, made all the telephone calls. She was a trained ART adherence counselor and had received in-person ethical training in working with people living with HIV through an FHI360 project.

Data collection

Semi-structured in-depth interviews were conducted from February to April 2016 by the first author and two research assistants (one male and one female). Interviews were conducted in either Twi or Ga and occurred at the recruiting hospitals (56%) or participants' homes (44%). An interview guide was pilot-tested with four individuals before data collection. Key topics covered included experience as a mother living with HIV, HIV diagnosis and disclosure, caring for LBW and NBW infants, and ART treatment and clinical visits in the postpartum period. The interviews lasted from 20 minutes to more than an hour. Twenty-six of the thirty interviews were audio recorded and transcribed verbatim, while handwritten notes were taken for the four others who did not want their interviews recorded. Participants also completed a structured questionnaire that captured socio-demographic characteristics, HIV history, and birth outcomes. Information on birthweight was extracted from medical charts.

Analysis

Data collection and preliminary analysis occurred concurrently, using methods adapted from grounded theory [26]. The field team held regular audio-recorded debriefing sessions to identify salient themes in the interviews. After the first seven interviews, the team formulated a working theory about the linkages between LBW and ART adherence and retention. During subsequent debriefing sessions, new data were compared to the working theory to enhance, confirm, or discard aspects of the theory. Sampling of participants was tailored to maximize understanding of elements of the working theory. Data collection ceased after reaching data saturation.

Following data collection, we inductively coded the transcripts. The first four transcripts were coded line-by-line. The codes were refined to eliminate redundancies and grouped under categories, based on underlying themes. The transcripts were then coded systematically in Atlas.ti. Each theme was examined for its presence, saliency, or uniqueness in interviews with mothers with LBW and those with NBW infants. We grouped the themes under positive and negative influences of LBW on engagement in HIV care. Memos were kept to enhance this process. In this paper, we define retention in HIV care loosely. It encompasses any missed visits for a clinical appointment to collect ART.

Ethics

Ethical approval was received from the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No. 6651), the Ethical and Protocol Review Boards of the Ghana Health Services (ID: Ms-Et/M.2-P4.1/2015-2016) and the

University of Ghana Medical School (ID: GHS-ERC 16/09/15). All interviews were conducted with participants' informed consent. Participants were compensated with $3 and a pack of diaper. All women who were no longer receiving treatment were encouraged to re-engage in care.

RESULTS

The majority of the 30 participants were recruited through the maternity clinics (47%) and one of the pediatric HIV treatment centers (30%). The mean age of mothers and infants were 35 years old [range, 24-44 years] and 5 months old [range, 5 days to 12 months], respectively. About 68% of the mothers had more than a primary school education, and 96% were either married or cohabiting. The mean time of the mothers living with HIV was 4 years. The mean birthweight in the LBW group was 1.88 kg and 3.01 kg in the NBW group. On average, mothers had two children (See table 1).

Care for LBW infants had both positive and negative influences on maternal engagement in HIV care for her own health. The negative influences included caregiver burden, stigma, and prolonged infant hospitalization. The positive influences included maternal motivation to survive and take care of the infant, as well as frequent contact with the health system for infants' health. All the quotes used in this paper are from mothers with LBW infants.

Negative influences of caring for LBW infants

Caregiver burden

In contrast to mothers with NBW infants, two-thirds of mothers with LBW infants repeatedly spoke about caring for their newborns in terms of suffering. The concept of *suffering* embodied significant physical and emotional toll—dimensions that define caregiver burden:

> *There was a lot of suffering…In feeding him, I suffered. At times, I had to pump the breast milk into a feeding bottle and give it to him on the bed. I did this until he turned 40 days old… [Even] after the 40 days, he still looked very tiny, like we just gave birth to him...*

Most participants' narratives suggested that caregiver burden contributed to mothers' incomplete ART adherence. Mothers used the phrase '*time beats me'* to capture a delay, distraction, or forgetfulness to take ART at scheduled times.

> *Sometimes, time beats me. I usually take my medicine at 8 PM, but when time beats me… I do not take it again since we were told at the hospital not to take it.*

Most of the mothers were on a triple combination pill twice a day, while a few were on a triple combination pill once a day. Several of the participants' accounts indicated that they put significant pressure on themselves to stick to their treatment schedules. When *time beat* the participants, most of them reported taking ART a few

hours later, but a few missed a complete day: *"Two mornings ago, time beat me and I didn't take the drugs. It has happened about twice now."*

Both mothers with NBW and LBW infants reported being *beaten by time;* however, this experience was more commonly described in interviews with mothers with LBW infants (11 out of 15) than in those with NBW infants (4 out of 15). The mothers' narratives suggested that the LBW infants slept less well, cried more, and demanded to be held more often than the NBW babies. Many mothers emphasized that these occurrences made mothers more likely to be *beaten by time*. In speaking about ART adherence, one mother shared her experience with her infant:

> *He likes crying … and always wants to be held and he does not like sleeping much. He delays me. Some children can even cry more than my child, and when this happens, it makes the mother distracted. She has to stop what she is doing to attend to the child.*

While burdens of caregiving were most saliently recognized as a challenge to full adherence with ART regimens, some women also noted that caregiving responsibilities could interfere with their ability to consistently attend their own HIV appointments. This difficulty, as mothers discussed, was related to a combination of *time beat me* and caregiver burden challenges.

Participants' descriptions of time related to two overlapping issues: 1) a 10:00 AM time that the HIV treatment centers had set for patients to report by, and 2) the time

participants felt they needed to be at the hospital to avoid long queues. One mother explained that when mothers are *beaten by time* they often would not attend their own HIV clinic appointments because arriving late would result in denial of services or a long wait with their babies.

> *It is very difficult… I have an older son, another one, and this child. When you wake up you have to prepare and take those children to school or find someone to take care of them. Then you have to come to the clinic …. Sometimes you get here [HIV treatment center] late… It is really hard. If you are not determined, you say forget it, I am not going to go this time…So sometimes the mothers' feel that time has beaten them and they won't come. You get tired.*

Stigma toward LBW infants and their mothers

Another key theme that emerged from the interviews is stigma toward mothers with small babies and their infants. Mothers' narratives show that the stigma was because the babies' physical appearance deviated from what is considered normative for newborns.

Half of the informants with LBW infants discussed experiencing or fearing stigma, while none of the mothers of NBW infants discussed this. The majority of those who experienced the stigma reported that their babies were small or very small at birth, which did not always correspond to the newborn's actual weight in the birth record.

As a result of the stigma, most mothers with very small babies described how they intentionally avoided going outside with their babies or regulated visitations to see them. One participant's comments illustrate this theme: "*So I couldn't even bring the baby out. I couldn't. If someone saw it [the baby], the person will think: "what kind of a 'thing' has this woman given birth to…?"* Another recollected: *"because the child was small, they used to whisper among themselves and when they saw me coming, they stopped."*

Most of the participants who experienced stigma reported depressive symptoms, particularly prolonged sadness. When speaking about how her neighbors gossiped about her, one respondent expressed: "*As for this case [i.e., baby being small and the gossiping], it made life so hard for me. Whenever I looked at my child, I started crying. I stayed indoors and cried many times."*

Mothers related that because of the stigma, they generally avoided taking public transportation to prevent unwelcomed stares; they preferred to take a taxi instead. For most informants, taking a taxi was costly and created challenges for some of them to attend a clinical appointment. One mother spoke about her struggles: "*As for the medicine, I am able to take them, but it is going to the hospital that is the most difficult for me."* She explained:

> *"It is not easy at all. You have to pay 30 Ghana cedi for a taxi, and on top of that, you have to think about what you will eat. You will see people selling food on the street, and*

you will want to buy some to eat. Before you realize it, the cost adds up to about 40 Ghana cedi.

This participant's report and others suggested that the experience of stigma created challenges for visiting the HIV treatment centers, but not for taking ART.

It is important to point out that mothers with NBW infants also preferred to take taxis with their newborns to seek HIV care, but not for reasons relating to stigma. Many felt that crowded public transportation exposed their newborns to diseases; thus, they preferred taking taxis.

Mothers with LBW infants generally did not directly associate the depressive related symptoms with not following-up on their HIV care or taking their ART.

Prolonged infant hospital admissions

Prolonged infant hospitalization contributed to incomplete ART adherence and missed visits. Ten of the 30 mothers reported that their infants had been admitted to the NICU; eight of these ten infants were LBW. Two were readmitted to an emergency ward after their first NICU admission. The duration of hospitalization ranged from 2 days to a full month. Among those who were admitted, about half of their mothers reported not taking their ART because they forgot them at home or thought they would not have a prolonged admission: *"Since my water broke, I thought I would not stay long there and so I did not carry my drugs with me…"* We witnessed firsthand how two of the women could not leave their sick infants and visit an HIV treatment center for their own ART.

Positive influences of caring for LBW infants

Motivation to survive and take care of infant

While the negative consequences of caring of LBW infants on ART adherence and retention in HIV care were more frequently mentioned, we did find that caring for LBW infants in some cases could also have a positive impact. Many mothers' accounts indicated that motivation to live and care for an infant could increase ART adherence and retention in care.

When asked about reasons for taking ART and why other mothers struggled to take theirs, often mothers with NBW infants attributed their reasons to a desire to prevent mother-to-child transmission of HIV and be healthy. Mothers with LBW infants cited similar motivations; however, they more frequently stated that they wanted to live and care for their children: "*The mother [who is not taking her ART] is not ready to fight for her life in the sense that you have to live for your baby."* This theme was more salient among mothers with very LBW or sick infants.

Frequent contact with the health system for infant's health

The poor health of LBW infants often brought many of the mothers into frequent contact with the health system. For a few mothers, this created an opportunity to re-engage in HIV care because of a health worker's intervention, coupled with maternal receptiveness to advice and willingness to practice new behaviors for the sake of the baby.

Some mothers with LBW infants had to visit the hospital multiple times to attend check-ups for their children's health. These visits benefited two participants who had

stopped taking their ART during pregnancy for more than five months because of side effects. In both situations, a health worker enquired about the mother's engagement in HIV care during a visit for the child. They were then referred to the HIV treatment center. One of the two mothers explained her situation:

> *If it wasn't for the fact that I brought my child to complain about her scratching her eyes, and was questioned about my drugs [ART] …I would still have been home. I would not have come to the hospital for my own care*.

Because pediatric services are provided separately from adult HIV care services, mothers had to make contact with the adult HIV treatment center themselves. Both of the above mothers visited the ART treatment center and resumed taking ART because they were responsive to advice given in the pediatric ward: *"I was glad that we were advised to continue with the drugs… what they tell us, that is what we will obey*". None of the mothers with NBW infants indicated that they re-engaged in care as an indirect result of seeking services for their babies.

DISCUSSION

Our study indicates that caring for LBW infants affects maternal ART adherence and retention in HIV care among postpartum women living with HIV in Ghana. Because of caregiver burden and prolonged hospital stays, mothers with LBW infants reported facing more difficulties in adhering to ART and keeping clinical appointments for their

own HIV care compared with mothers with NBW infants. We also found that on few occasions, caring for LBW infants facilitated re-engagement in HIV care.

To date, studies conducted in sub-Saharan Africa have only examined the relationship between poor maternal adherence to ART during pregnancy and the subsequent delivery of a LBW baby. On the contrary, our study explores how caring for a LBW baby affects ART adherence in the postpartum period. In a clinical trial conducted in Zambia, pregnant women who were non-adherent to a single-dose of nevirapine were 4.6 [95% CI: 1.3-20.1] times more likely to give birth to a LBW baby compared to those who were adherent [27]. In addition, women who gave birth to LBW babies were also 2.33 [95% CI: 1.35-4.02)] times more likely not to have taken the medication at the right time compared to those who gave birth NBW babies [27]. Moreover, across four sub-Saharan African countries, Stringer et al. also found that non-adherence to a single-dose of nevirapine during pregnancy was associated with a 34% [95% CI: 1.11-1.62] higher odds of having a LBW baby at birth [28]. In our qualitative study, we found that caring for LBW infants after childbirth contributed to incomplete ART adherence. Collectively, these two studies and ours suggest that ART non-adherence during pregnancy may contribute to a birth of a LBW baby, and caring for a LBW infant, may, in turn, create challenges for ART adherence. While PMTCT programs have shifted from a nevirapine-based service to Option B-plus since the earlier studies, our study highlights that the challenges mothers face with ART adherence remain.

Caregiver burden was one mechanism we found linking caring for LBW infants to incomplete ART adherence. Some have speculated that demands of caring for a

newborn are likely to contribute to lower retention in HIV care in the postpartum period compared with the antenatal period [3, 7, 11]. Our results suggest that this relation may not be pertinent to all mothers, but more so to those with sick or LBW infants. As our participants reported, the newborn behaviors that made them forget or delay taking ART—poor sleeping habits, excessive crying, and needing to be constantly held—appeared to be less common among NBW infants. Mothers with NBW infants were less likely to report that they experienced caregiver burden.

Research has shown that caregivers of sick family members are less likely to use preventive services for their own health [13]. One explanation often cited is that caregivers are more likely to prioritize the health of the care recipient over their own [13]. In our study, caregiver burden translated to a missed visit because of health system factors more so than individual factors. Mothers did not want to stay in long queues or have health workers chastise them for coming later than a hospital set appointment time. Thus, a delay at home because of caregiver burden led to a missed visit. A missed visits is important because, among adults living with HIV in sub-Saharan Africa, Ware et al. have shown that missed appointments can potentially result in a reluctance to return to care and contribute to long-term disengagement [29].

Our finding that stigma created challenges for mothers to attend their clinical appointments for ART is consistent with findings from several studies. Studies have shown that the experience of stigma undermines utilization of health services, including HIV care [11, 30]. In a systematic review, high levels of stigma were strongly correlated with lower levels of use of HIV care services [31]. We found that, in response to stigma, mothers with very small babies relied on private modes of transportation to access HIV

care—in this case, taxis—to prevent others from seeing their babies. This mode of transportation increased the financial cost of accessing ART and created challenges for keeping appointments. Our results thus extend knowledge of how stigma affects health utilization among postpartum women living with HIV in Ghana.

Limitations and Strengths

The study has some limitations. The participants were urban women recruited from tertiary hospitals. Thus, their experiences may not reflect the challenges rural women, or women in a non-tertiary setting face in Ghana. Future studies conducted at different sites will be needed to triangulate and confirm the transferability of our study results. Strengths of our study include a focus on tertiary hospitals where studies show that retention in HIV care is lower than non-tertiary hospitals. Also, we documented the experiences of a population of women whose adherence challenges in the postpartum period has not yet been studied in Ghana.

Implications for Practice

To effective support the HIV-care needs of mothers with LBW infants, we recommend improved access to HIV drugs in pharmacies associated with NICUs, home visitation for delivery of ARTs postpartum, and prenatal guidance on medication reminders and hospital planning. We also recommend that during prolonged admission of infants, clinical practitioners at pediatric care units ask about caregivers' access to ART and adherence. This step will ensure that mothers without ART are provided with

treatment. This means that ART should be available at pharmacies associated with NICUs, which is not currently the case.

Given the caregiver burden and the prolonged sadness that our participants faced, health workers could consider delivering ART to the mothers at home. In addition to enhancing access, such a model will allow health workers to refer mothers with depressive symptoms to mental health services. Also, health workers could accommodate the needs of postpartum women by being more flexible with the time that mothers have to report for care. They could consider ways to reduce wait time. Following these recommendations could mitigate the contribution of caregiver burden to missed visits.

Moreover, counselors of pregnant women living with HIV at antenatal clinics should encourage them to prepare in advance to have ART with them when they report for labor. Health workers can easily incorporate this counseling into education on birth preparedness that already occurs in this setting [32]. Also, due to the relation between caregiver burden and missed doses of ART, interventions that promote cues to action, such as alarm reminders, may be helpful to mothers. Resources that provide tips on how to reduce caregiver burden will also be beneficial to mothers, including how to get social support.

CONCLUSION

The postpartum period is a challenging time for engagement in HIV care among women. Our results point to how demands of childcare can simultaneously create difficulties for mothers to care for their health and also lead to opportunities for engagement with the health system. The findings indicate that mothers with LBW infants

need social support to reduce caregiver burden. This reduction will, in turn, increase their ART adherence and follow-up on HIV-related clinical appointments. Also, interventions are needed at the individual and health system levels to help mothers stay engaged in HIV care during a prolonged hospital stays. Our qualitative study provides an opportunity for new research to quantitatively test the potential association between LBW and lower engagement in HIV care among postpartum women in Ghana.

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Table 1: Background characteristics of study participants and their infants

Characteristics	N (%)
Categorical Variables	
Birth weight status	
LBW	15 (50)
NBW	15 (50)
Education level	
No formal education	1 (4`)
Primary school	8 (29)
> Primary School	19 (67)
Marital status	
Married	24 (80)
Cohabitating	5 (17)
Single/widowed	1 (3)
Ethnicity	
Akan	12 (40)
Ewe	7 (23)
Ga	3 (10)
Other	8 (27)
Occupation	
Trader	14 (46)
Seamstress	5 (17)
Other	11 (37)
Time of HIV diagnosis	
Before index pregnancy	21 (70)
During index pregnancy	8 (27)
During postpartum	1 (3)
Continuous Variables	**Mean (range)**
Maternal age (years)	34.80 (24-44)
Number of children	2.09 (1-4)
Number of years living with HIV	4.14 (0.4-16)
Mean birth weight (kg)	2.49 (1-3.5)
Infant age (months)	4.80 (0.17-12)

CHAPTER SIX: CONCLUSIONS

Figure 7: A word cloud of all of the participants' quotes used for the three manuscripts

SUMMARY OF RESEARCH FINDINGS

Overview

The results of this dissertation, taken together, identify the unique challenges postpartum women living with HIV in Accra, Ghana face in simultaneously taking care of their newborn and attending to their HIV-related needs. The findings draw attention to how stigma and caring for LBW infants impact postpartum women's mental health and engagement with HIV care. In Figure 2 below, I present a conceptual framework that unifies the central themes discussed in Chapters 3-5. The framework illustrates the key barriers to retention in HIV care and ART adherence in the postpartum period.

For simplicity and clarity, I classify these themes as either "distal" or "proximal" barriers to help distinguish between barriers that are central vs. those that are peripheral in nature. Proximal barriers are factors that commonly influenced participants' retention and ART adherence in the postpartum period. These are caregiver burden, insufficient household finances/transportation cost, ART-related side effects, and prolonged hospital stays. Distal barriers are the key underlying issues that contributed to the proximal factors. These included structural factors (health system service delivery, unemployment due to childbirth), community (stigma) and interpersonal (newborn care/newborn health, HIV disclosure, and social support) level factors.

Below, I describe the proximal barriers in the order in which they appear in the framework. I weave into each description the underlying distal barriers. I conclude this chapter by indicating the research and public health implications of this dissertation.

PROXIMA AND DISTAL BARRIES TO ENGAGEMENT IN HIV CARE IN THE POSTPARTUM PERIOD

Caregiver burden

Caregiver burden resulting from newborn care was a dominant theme when participants discussed their reasons for incomplete adherence to ART and missed clinical visits for HIV care. As mothers reported, this burden made them forget or delay taking their ARTs. Caregiver burden also led to delays in being *on time* to receive ART at the health facility. Not reporting on time, as elucidated in Chapter 5, increased the likelihood of being denied service for the day or staying in a long queue. To avoid these repercussions as mothers reported, some postpartum women missed visits when they feel *time has beaten* them.

This theme featured more prominently in the interviews with mothers with LBW infants than in the interviews with mothers with NBW infants. Some studies have also noted high caregiver burden in mothers with children infected with HIV[1], suggesting the significance of infant health on the experience of caregiver burden among mothers living with HIV.

The findings clarify aspects of childcare that influence maternal engagement in HIV care. Prior studies had speculated that childcare demands might play a role in maternal ART non-adherence and poor retention in the postpartum period[2-4]. Some, relying on medical charts review, have attempted to capture this demand by the number of children a mother bears[2, 3]. They found no statistically significant relationship between parity and follow-up on HIV care in the postpartum period. Our qualitative study

suggests that caregiver burden, a construct that embodies an intensive physical, emotional, and psychological aspects of caregiving, may be a better measure that can illuminate the relationship between childcare and retention than the number of children. Our study demonstrates that it might be the intensity of childcare, marked by a baby's health or demand for more physical care (such as wanting to be held all the time), that may hinder mothers in following-up on their care or taking ART.

Also, it is important to clarify that mothers' reports indicate that caregiver burden may be related to intermittent missed visits more so than prolonged discontinuation from care. Our results suggest that future studies that seek to examine the relation between childcare and retention in HIV care in the postpartum period should endeavor to assess caregiver burden, in ways which have not occurred to date [5-7].

Insufficient financial resources

Another important proximal barrier strongly tied to newborn care and influenced by social, interpersonal and structural factors was insufficient financial resources. Among our participants, insufficient financial resource was the leading reason why mothers in our study missed visits or discontinued receiving HIV care. Based on their accounts, I contend that a major reason why retention is lower in the postpartum period than during pregnancy in the Ghanaian urban context, may be differences in the financial costs of accessing HIV care during these two periods. By promoting this hypothesis, this dissertation shifts the focus from individual-level factors as reasons for poor retention in the postpartum period and points to social and economic conditions as principal reasons.

Several distal barriers that were structural and interpersonal in nature worked either to increase the costs of accessing HIV care or constrain the financial resources needed to attend a health facility to receive such care. The most prominent of these underlying factors was ***newborn care/newborn health,*** which was also integral to how HIV disclosure, social support, and stigma affected follow-up to receive ART among participants.

We found that out of a desire to protect their babies' exposure to diseases, postpartum mothers in our study preferred to use private modes of transportation or taxis rather than crowded public buses *(trotro)* to follow-up on their care. During pregnancy, however, they were comfortable taking the public buses. Taxis are significantly more expensive than *trotros*. Consequently, in the postpartum period, we observed that the economic burden of accessing HIV care was higher than during pregnancy. This finding, which has not been reported previously in the literature, offers one reason why in Ghana retention in HIV care patterns change before and after childbirth[3].

HIV non-disclosure, social support, and stigma were related to this transportation phenomenon. HIV disclosure and social support both functioned to alleviate the financial challenges associated with traveling with a newborn by making childcare or funds available to women. Social support freed mothers from traveling with a newborn to a clinical appointment. This liberty allowed them to take less expensive modes of transportation. HIV non-disclosure, a product of HIV-related stigma, restricted mothers' access to instrumental social support. Participants' accounts suggest that it deterred some mothers from asking their partners or relatives for funds to attend clinic

visits or get help in carrying their babies to their visits. Thus a lack of social support and HIV non-disclosure impacted mothers HIV care negatively.

We also found that to avoid maternal blame, some mothers with LBW infants did not disclose their HIV status to their partners as a result of having a small baby. They felt that others, such as relatives and friends, will perceive that their HIV infection was responsible for their babies' size. Already, as shown in Chapter 5, comments from family members and relatives suggest that maternal blame was a key part of the lived-experience of mothers with small babies.

This finding expands our knowledge of the factors that contribute to HIV non-disclosure among women in Sub-Saharan Africa. Several studies have demonstrated that lack of HIV disclosure leads to ART non-adherence and missed visits for HIV care[5, 6]. Fear of violence or relationship strain, a challenge to one's motherhood status, and discrimination are common reasons why women do not disclose their status to others[5, 6]. The extent to which having a very LBW or preterm infant deters such disclosures within the Ghanaian context has not been reported. Our result suggests that for some mothers intention to disclose HIV status after pregnancy may decrease after having a small baby.

Stigma, both relating to HIV and small babies (Chapter 4) increased the economic burden of accessing HIV care through their effects on transportation costs. HIV stigma, as participants recounted, made them choose to receive ART at health facilities that were distant from their homes to avoid accidental disclosure. This distance, coupled with a maternal preference for taxis, elevated the cost of seeking care in the postpartum period. Stigma toward having a small baby affected the choice of transportation, in particular, the use of taxis to minimize negative reactions from others toward the mother-child dyad.

These results add to the research on stigma relating to baby size by demonstrating its impact on mothers living with HIV. Prior studies had documented the influence of this stigma on maternal mental health and social relations[8, 9], but had not examined this stigma in the context of HIV. Our findings show that the impact of stigma relating to babies' size extends beyond mental health; it creates challenges for affected mothers to follow-up on their HIV care.

While social and interpersonal factors like stigma and HIV disclosure that shape women's engagement in HIV care have been well documented, the effects of structural level factors need further consideration[6]. In our study, we found that one way structural level factors affected retention in HIV care was that they created additional costs in the postpartum period and reduced the money available for mothers to access HIV care. Among our participants, unemployment as a result of childbirth, out-of-pocket cost for maternal health care, and unintegrated postpartum maternal, child and HIV services were the major structural obstacles. They featured less frequently in the interviews with informants, but were nevertheless important.

Most of the participants in our study were self-employed, as traders, beauticians, and seamstresses or worked in occupations that paid a daily rate. Many of the participants, like Hawa (in Chapter 3), indicated that they stopped working or became ***unemployed to care for their newborn*** after childbirth. This situation resulted in some mothers having less or no money of their own. As several participants explained and we also observed, women without personal income faced the most difficulties in accessing HIV care—they had to rely on others for money to meet the cost of attending their

appointments, and when this support was not available, it led to missed visits and discontinuation from care.

Childbirth was also accompanied by ***out-of-pocket health care costs*** as a result of the fiscal challenges of the Ghana's National Health Insurance Scheme. In Chapter 2, I explained that the insurance scheme is supposed to pay for pregnancy, childbirth and postpartum services. Nevertheless, at the time of data collection, several of the participants who were insured reported paying out-of-pocket for childbirth-related costs. The few women who could not pay were detained by the hospitals until they paid. For low-income families like Hawa, whom I described in Chapter 3, their narratives show that these childbirth health care costs created debts or significant financial hardships within households. These difficulties, in turn, made less money available for mothers to attend HIV care appointments.

Lastly, the ***unintegrated maternal, child and HIV services*** for mother and child at the two facilities demanded that women make several visits within the postpartum year for these services. As described earlier, maternal preference for a private mode of transportation for travels with the newborn made these visits economically burdensome, which constrained financial resources available to seek HIV care.

Uncovering these structurally related factors is a meaningful contribution to the literature on retention in HIV care in the postpartum period as most studies have focused on individual-level factors such as, maternal motivations and beliefs[6, 10].

Experience with HIV-related side-effects

The individual level proximal barrier that was prominent in participants' experience was ART-related side effects. They were the second most reported reason for discontinuation from HIV care in the postpartum period after transportation costs. As reported in Chapter 3, participants' stories show that the experience of ART side-effects during pregnancy created a reluctance to return to care during the postpartum period because of a fear of re-experiencing those same effects. It also made it easier for mothers to disengage from care for other reasons. This barrier occurred in a context where there was no institutional tracking mechanism to identify whether participants' reports of side-effects resolved or needed further management.

Prolonged hospital stays

The last of the proximal barriers in the conceptual model that contributed to missed visits and ART non-adherence was prolonged hospital stays of the newborn. Based on participants' accounts, some mothers did not anticipate that their baby would be admitted to the hospital for a prolonged period after childbirth; thus, they did not make arrangements to have their ART with them or request their family members to have them brought to them. Some also forgot their ARTs. Moreover, during admissions, a few of the mothers missed their visits because they could not leave their children at the hospital ward to attend an appointment. This finding is new and accentuates the uniqueness of the challenges postpartum women face to engage in HIV care.

Part of the reason why prolonged hospital stays were impactful was also that maternal, neonatal, child health and maternal HIV care services in the postpartum period

occurred in silos at the study sites. In an integrated care model where prevention of mother-to-child transmission of HIV is a priority, hospitals would have asked mothers during a prolonged hospital admission about the drugs. They would have been able to facilitate or provide ARTs to those who did not have theirs. Participants' reports indicate that they were not asked about their ARTs during their hospital stays.

STRENGTHS AND LIMITATIONS

One main limitation of this investigation is that all participants were drawn from an urban area. As reported earlier, about 46% of Ghanaians live in a rural setting[11]. The living arrangements, access to transportation, systems of beliefs, HIV care services may vary for rural versus urban women. Consequently, the findings of this study may not be transferrable to these settings.

In addition, data used in the study were cross-sectional. Several of the themes relating to small babies, such as maternal detachment and reluctance to show the newborn improved with time, as newborns gained weight. Also, as study participants explained, their challenges with following-up on their HIV treatment in the postpartum period was intensified in the first six months. Using a prospective design, this study could have produced deeper insights about how participants' experiences change over time.

This dissertation has several strengths. First, being a Ghanaian able to speak Twi allowed me to conduct high-quality interviews. I conducted about half of the interviews and understood the cultural relevance and context of participants' experiences. My fluency in the local language also allowed me to listen to the audio recordings of the interviews; thus, I did not have to rely solely on the English transcripts. My engagement

in the data collection and similar cultural background helped elicit rich descriptions from participants.

Second, an essential requisite for a rigorous qualitative study is that the results are credible. Credibility deals with confidence in the integrity of the findings. I took various steps to ensure that the interpretations of participants' experiences were not entirely my own construction. During data collection, I held multiple debriefing sessions with my team. We thoroughly discussed each caregiver's experience and that of all the study participants. Our interpretations as a team are consonant with the conclusions reported in this dissertation. Also, in drawing on principles of grounded theory, I used an iterative analytical process to develop an understanding of the data. I tested assumptions and theories during the data collection. I compared new interviews with theories we had developed from the narratives of prior participants. This process allowed me to refine my understanding of participants' experiences and reach conclusions that are consistent with the data.

I also watched my own sister live through various aspects of stigma toward small babies prior to this study (ex. maternal attachment, reluctance to show the baby to others, and maternal blame). I used this initial personal experience to inform the data collection instrument for this study, of which I refined after pilot testing. In addition, I was also able to use her experience to build rapport with mothers in our study. This facilitated their sharing their stories with me. Notwithstanding, my undergraduate thesis focused on neonatal care in Ghana, and I encountered similar stories when I talked to mothers about small babies. These experiences and precautions give me confidence in the findings.

IMPLICATIONS FOR PUBLIC HEALTH

The implications of this study for public health have been discussed in Chapters 3-5. Hence, only the broad principles that should guide intervention development are echoed here.

To increase retention of postpartum women living with HIV in Ghana, the findings support strategies that integrate HIV, maternal, and child health services; diminish the economic burden of accessing HIV; and promote social support. In the current HIV policy environment in Ghana, women living with HIV receive free ARTs, which eliminates the cost of ART as a barrier to acquiring HIV treatment. This provision, however, does not fully address the individual financial cost of obtaining HIV treatment. As I have explained, the postpartum period brings significant pressures on the finances of families. Without interventions to support families to meet their monetary obligations to access care, the problem of poor retention in the postpartum period may persist.

These efforts should be complemented with an integrated model for delivering maternal, HIV and child health services. As our data illustrate, in the postpartum period, women juggle multiple appointments to get health care for themselves and their children. Streamlining services such that in the first year, the mother and child can receive HIV, maternal, and child services in the same place could greatly benefit mothers. For example, we found that some mothers attended the required visits for postnatal and pediatric HIV care, yet they had been out of HIV care for several months. A strong integration of services would ensure that mothers' efforts for their children translate to benefits for their own health as well.

Another area that requires attention is the psychological health challenges of women living with HIV with very small babies. Ghana was progressive in passing a Mental Health Law in 2012 that mandates and makes provisions for funding of mental health services at the primary care or community levels (see Chapter 2).

Some funding connected to these mental health services could be used to support groups for mothers with small babies [12]. In a pilot study, mothers with unwell babies at the NICU at Korle Bu participated in a support group facilitated by a trained psychologist. Participants reported that the group provided opportunities for them to share their emotions, be inspired by others' stories and have an optimistic outlook about their children, and gain skills in communicating about their feelings to others [12]. Importantly, it also allowed new mothers to receive advice and guidance from mothers who had been at the NICU longer. The results of that study underscore the potential significance of harnessing the experience of those who have already lived through caring for a small baby.

IMPLICATIONS FOR RESEARCH

This research was exploratory in its scope, and as such, several opportunities exist to confirm and expand upon its conclusions. Epidemiological studies conducted in Ghana on stigma relating to a baby's size are a natural next step.

To date, most of the research on stigma relating to a baby's size have mainly been qualitative in design. Consequently, we have some grasp of the nature and source of the stigma relating to baby size. However, we have limited information on the prevalence of and variations in susceptibility to this stigma. Prevalence studies will help determine

the burden of the stigma at a population level. For program planning and resource allocation purposes, identifying populations that are most susceptible to stigma is important. This study provides a starting point by suggesting potential risk factors: no history of LBW or preterm delivery, living in a household with multiple families, newborns age and size, and living with HIV.

Another natural follow-up on this study would be to quantitatively study LBW as potential risk factor for ART adherence and missed visits. This recommendation reflects recent calls in the literature to examine related interpersonal factors that affect women's utilization of HIV care in the postpartum period [6]. The data from this study provide evidence for focusing on LBW as a potential risk factor for ART adherence and missed visits for HIV care. Currently, I have pilot funding from the National Institute of Health to pursue this research in Ghana.

Other areas of study could be social science research on the experience of men about their partners' birth of a small baby. Topics could include how men perceive their baby, cope with the stigma, and view the experience of their partners. Also, more in-depth research is needed to understand the circumstances that lead to and occur when a newborn is left in the NICU with health workers. Questions remain around how caregivers relate to their families, how their families response to them, and how reconnection occurs in such a context

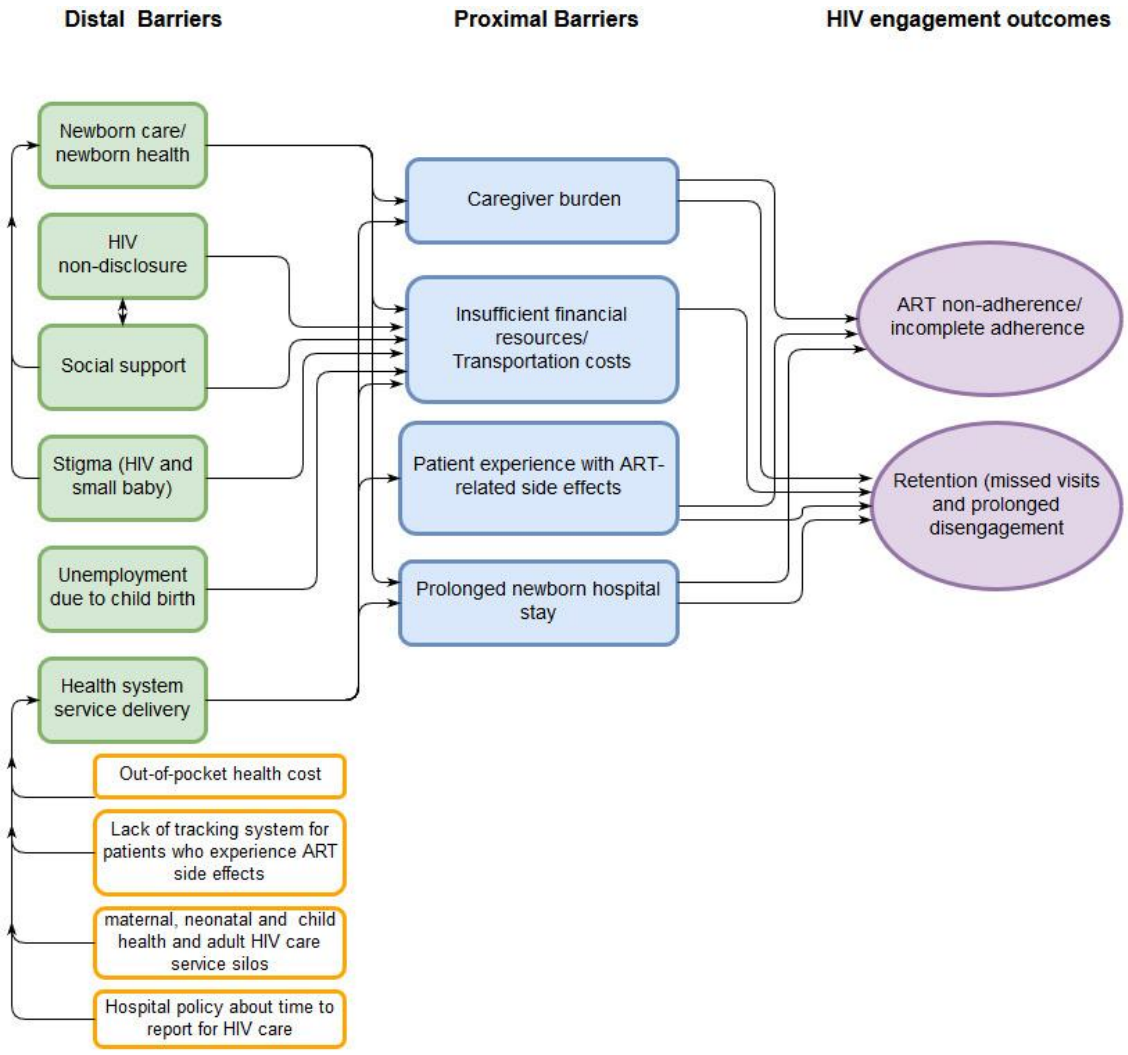

Figure 8: Proximal and distal factors linked to ART non-adherence and retention in HIV care among postpartum women living with HIV in Accra, Ghana

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APPENDICES

Approved: 09December 2015
IRB No.: 00006651

IN-DEPTH INTERVIEW GUIDE

Interview Objective

At the end of this interview, you should able to:

1. Describe the participant's lived experience of being a mother living with HIV and also for caring for a newborn.
2. Understand the social significance and consequences of having a low birthweight or preterm baby.
3. Describe aspects of newborn care or characteristics of the newborn that most influence retention in HIV care and adherence to anti-retrovirals in the postpartum period
4. Identify challenges mothers have in caring for newborn in general

Steps to the Interview

1. Familiarize yourself with the questionnaire before hand
2. Complete the identifier information and interview characteristics
3. Introduce yourself to participant
4. Read the consent form and ask permission to record interview
5. Reiterate the goal of the interview
6. Turn on the recorder, if permission was granted.
7. Start interview and take copious notes as you go
8. When interview is complete, thank the mother and

Guidelines

1. Build rapport early on during your introduction
2. Listen and express interest in what the participant is telling you
3. Use probing to help participant expand on their answers (repetitions, silence, tell me more, give me an example, etc)
4. Let the participant determine the pace of the interview
5. Interview questions are only a guide, so let participant determine the interview's direction (should be within topic however)
6. Make sure interview recorder is on and close to the participant.

Introducing Yourself:

Hello. My name is _____. I am one of the project staff on this research study. Thank you for meeting with me today. I'll be having a conversation with you today about what is like to care for a newborn, to be a mother and live with HIV. I also want to hear about the experiences you've had in taking care of your health and your HIV infection. Please there are no right or wrong answers. I just want to hear your opinion.

	SECTION 1: BIRTH EXPERIENCE, CAREGIVER REPRESENTATIONS AND PERCEPTIONS
1.	Could you describe what happened on the day you gave birth to your baby?
	a. How did you get to the hospital? b. What happened when you got to the hospital? c. What was it like giving birth at this hospital? d. How do you feel about the care you received? e. Were there any complications with you or your baby after the birth? What were they?
2.	Could you describe your baby to me when he/she was born?
	a. What did the baby look like? **If baby was small or preterm, ask what she thinks the cause of it.** b. How did he/she compare to other babies? c. How did he/she compare to your previous births? d. What do people say about baby sizes *(probe about small and very small babies)?* e. What do people say about preterm babies?

3.	Could you describe what it has been like being a mother to this baby from the time of its birth up until now?
4.	Were there times when caring for your baby was difficult?
	a. If yes, could you give me examples of those difficult times? i. What made those times worse? ii. What made them better? iii. How did you deal with these difficulties? b. Are there things that could have been done to make caring for your baby easier?
5.	Tell me what your experience has been with feeding this baby?
	a. Explore reasons for breastfeeding and not breastfeeding

	SECTION 2: SOCIAL RELATIONS AND SOCIAL INTERACTIONS
	I am going to ask questions about your family, neighbors and friends concerning how they treated you after your birth.
1.	Tell me about the day when your___ saw your baby?
	a. Family (If partner is not mentioned, ask about him) i. When did you first let them see the child? ii. What was the reason why you let them see the baby at this time? iii. What was their reaction at the beginning? iv. How did that make you feel? v. How did they treat you since then? vi. How does your relationship with them now compare to when you were pregnant?
	b. Close friends i. How did you communicate with them about your birth? ii. How did you manage visitations from them? (probe *frequency, timing, access to baby)* i. When did you first let them see the child? ii. Who did you let see your child? What was the reason for those people? iii. What was their reaction when they saw the baby? iv. How did that make you feel? v. How did they treat you since then?
	c. Neighbors Repeat bi. to bv.
2.	How did you manage the appointments for hospital check-ups for your baby?

	a. When were you able to go? b. Did you miss any of the check-ups? *If yes,* what happened on the day that you missed? *If not,* tell me how you were able to go for all the checkups? c. How did you get there most of the time? How did you feel about taking that kind of transportation?

	SECTION 3: LIVING WITH HIV, ADHERENCE TO VISITS AND ANTIRETROVIRAL THERAPY
	I am going to ask you some questions about your feelings concerning having HIV and being a mother. Some of these questions may make you feel sad or anxious. You can skip any question you do not like.
1.	What has been your experience living with HIV as a mother?
	a. How has it affected the way you care for your baby? b. How has it affected life for you inside and outside of your home? c. How has it affected your health?
2.	Could you tell me what you have done for treatment?
	a. How have you been doing with taking your treatment according to instructions? i. *If she missed some of the treatment,* ask her to tell you more about the situation that made her not take her treatment ii. *If she hasn't missed any treatment*, ask her to tell you about how she is able to not miss any treatment b. If infant was ever admitted to the hospital, ask what happened with her treatment adherence during that time.

	Could you compare your adherence to treatment when you were pregnant vs. after birth of your baby?
3.	Could you tell me about your attendance at the HIV clinic? ***(If she missed some of her appointments, ask her to tell you about the situations that led to that. If she didn't miss, ask her what helped her to attend her appointments)***
	a. When did you decide to go to the HIV clinic after birth? b. What motivated you to go at that time c. Tell me about what you did with your baby when you attended your clinic visits? d. Could you tell me about the frequency of your visits? e. When you went to the HIV clinic for the first time after birth, could you walk me through what happened on that day? f. Tell me about your experience with visiting the HIV clinic for treatment.
4.	Could you compare your visits to the HIV clinic when you were pregnant vs. after birth of your baby?

SECTION 5: Option B and B-plus
I want to get your opinion about two ways of giving HIV medication to pregnant and breastfeeding mothers who test positive for HIV.
Option B: The pregnant mother or breastfeeding mother who tests positive for HIV is put on ARVs. After breastfeeding, she will continue with the ARVs for the rest of her life. She can't stop at any time. **Option B+:** The pregnant mother or the breastfeeding mother who tests positive for HIV receives ARVs. She will continue with the treatment through breastfeeding. She will stop taking ART after breastfeeding *only* when doctors determine her body is fighting the HIV well (CD4 cell count >350 cells/ul); otherwise she has to continue. She can stop and start at the doctor's recommendation.
Which of the options do you prefer? Tell me the reason behind your choice?

Is there anything more you would want to tell me about what we have discussed today?

NOTE: COMPLETE HIV HISTORY, BIRTH OUTCOME AND SOCIO-DEMOGRAPHIC BACKGROUND OF PARTICIPANT

SUMMARY OF INTERVIEW

Describe the setting of the interview?
What were the main topics you covered in the interview?
What are the main themes of this interview?

QUALITATIVE INTERVIEW: BASELINE QUESTIONNAIRE

SECTION 1: IDENTIFIERS				
1.	Woman ID	ID	[__ __ __]	
2.	Interviewer ID:	ID	[__ __ __]	
3.	Date of Interview	Day.Month.Year	[__ __. __ __. __ __] DD. MM. YY	
4.	Hospital Site	1= Korle Bu 2= Ridge Hospital	[____]	
5.	Location of the Interview	1= Korle Bu 2= Ridge Hospital 3= Community clinic 4= Home 5= Another private space 6= Other	[____]	If other, specify
6.	Was interview recorded	0= No 1= Yes	[____]	
7.	Form Status	1= Form completed 2= Consent Completed 3= Refused	[____]; [____];[____]	**Check all that apply** **If 3→ Stop**
8.	Interview start time	HH: MM	[____]	
9.	Interview time	HH: MM	[____]	
10.	Transcriber Code	ID	[__ __ __]	

SECTION 2: HIV HISTORY				
1.	When were you diagnosed with HIV? Was it before you were pregnant, pregnant or giving birth, or after birth	1= Before pregnancy 2= During pregnancy 3= Labor and Delivery 4= Postpartum 8= Refused 9= Don't know	[____]	
2.	Overall, how long have been living with HIV?	Years Months	[____]	
3.	When did you start HIV treatment? *[Probe about month and year]*	0=None Month : Year : 99=Don't know or refused	Month: ___ ___ Year: __ __ __ __	Write the date in the fomat indicated in the category column
SECTION 3: INFANT CHARACTERISTICS				
1.	How old is your baby now?	06-28 months 88= Don't knmow 99- Don't know	[__ __]	
2.	What was your child's size when he or she was born? Would you say, very small, small, average, large, very large	1=Very small 2= Small 3= Average 4=Large 5= Very large 8= Refused 9= Don't know	[____]	
3.	How many months were pregnant when you gave birth to your baby?	01-11months	[____]	
4.	Is your child HIV negative or positive?	0=No 1= Yes 2= Refused 9= Don't know	[____]	
5.	What is your child's gender?	1= Male 2= Female 8= Refused 9= Don't know	[____]	

SECTION 4: SOCIO-DEMOGRAPHIC CHARACTERISTICS				
1.	How old are you now?	14-55=years 99=Don't know	[__ __]	
2.	What is your religion?	0= None 1= Christian 2= Muslim 3= Traditional 4= Other 8= Refused 9= Don't know	[____]	**If 4→Specify below**
3.	What is your ethnicity?	0= Akan 1= Ewe 2= Ga 3= Hausa 4= Other 9= Don't know	[____]	**If 4, specify below**
4.	What was the highest education you completed in school?	0= No Education 1= Primary Education 2= Junior Secondary School 3= Middle Sch. Leaving Certificate 4= Secondary Education/ Technical 5= Tertiary Education and Above 8= Refused 9= Don't know	[____]	
5.	Aside from your own housework, do you do any work for which you are paid in cash or in kind?	0= No 1= Yes 9 = Don't know	[____]	**If 0→ skip to 10**
6.	a. What kind of work do you spend most of your time doing?	1= Trader 2= Seamstress 3=Hair dresser 4=Caterer 5= Government Service 6= Private service(salaried) 7=Other 9= Don't know	[____]	If 7→ Specify below
7.	Compared to other families, would you describe the amount of	1= Below average 2= Average 3= Above average	[____]	

	money your family has as below average, average, or above average?[van Bodegorn et al., 2009]	8= Refused 9= Don't know	
8.	What is your marital status?	0= Married 1=Co-habiting 2= Separated 4= Divorced 5= Widowed 6= Single 8= Refused 9= Don't know	[_____]

SECTION 5 : FOLDER REVIEW

1.	Infant weight at birth	Weight (kg) 99=Don't know	[__].[__]
2.	Gestational age at birth	01-44 months	[__][__]
3.	Infant HIV status	0=Negative 1= Positive 9= Don't know	[__]

NOTE: ENTER "1" FOR FORM STATUS ON PAGE 1

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Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

2005—2009 **Bachelor of Arts in Biochemistry; Minor in International Studies**
Albion College, Albion, MI
Graduated with magna cum laude and Honors

CURRENT POSITION

2016-Present **Director**, Center for Learning and Childhood Development-Ghana; www.clcdghana.org
2013-Present **PhD Candidate**, Johns Hopkins Bloomberg School of Public Health

OTHER PROFESSIONAL POSITIONS

2016 **Reviewer**, Journal of Positive Psychology
2014 **Reviewer**, Maternal and Child Health Journal

HONORS AND AWARDS

2015 Robert and Helen Wright Scholarship in International Health, JHSPH
2015 Student Assembly Merit Award, JHSPH
2011 Georgeda Buchbinder Award in International Health, JHSPH
2009 Edmund and Kathleen Jenkins Award for Outstanding Student Research, Albion College
2008 Stefan Kobiljak Jr. Pre-medical Scholarship, Albion College

2006 Cathy L. Young French Poetry Winner, Albion College
2005-2009 Dean's List, Albion College

TEACHING EXPERIENCE

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH

Teaching Assistant Positions

2015	Social and Behavioral Foundations of Primary Public Health
2015	Introduction to International Health
2014	Health Behavior Change at the Individual, Household and Community Level
2014	Qualitative Research Theory and Methods

Guest Lecturer

2016	Scale Development in Formative Research
2016	Social and Behavioral Foundations of Primary Public Health
2014	Doctoral Seminar in Advanced Medical Anthropology II

Guest Panelist

2016	Doctoral Seminar in Proposal Development
2015	Health Equity and Disparities Panel Discussion
2014	Doctoral Seminar in Proposal Development

PUBLICATIONS

- Surkan PJ, **Sakyi KS**, Strobino DM, Mehra S, Labrique A, Ali H, Ullah B, Wu L, Klemm R, Rashid M, West KP, Christian P. **Depressive symptoms in mothers following peri-natal and early infant loss in rural Bangladesh**: A population-based study. Annals of Epidemiology. 2016. 26:467-473

- Andrew A. Adjei, Peter Winch, Amos Laar, David J. Sullivan Jr., **Kwame S. Sakyi**, Judith K. Stephens, George O. Adjei, Isaac A. Boateng, Vivian N. Ama Aubyn, Chrysantus Kubio, Julliette Tuakli, Linda Vanotoo, Bernard B. Bortei, Maame Amo-Addae, Felix Sorvor, Nathaniel Coleman, Sarah Dalglish, Richmond Owusu, Tsega Gebreyesus, Edward Essuman, Rebecca Greene, Ezekiel Ankomah, Kiely Houston, Constance Bart-Plange, Samuel Salamat, Ebenezer A. Addison and Isabella A. Quakyi. **Insights into the Affordable Medicines Facility-malaria in Ghana: the role of caregivers and licensed chemical sellers in four regions.** Malar J. 2016. 15 (1):263. doi:10.1186/s12936-016-1307-5

- **Sakyi KS,** Surkan PJ, Eric Fombonne, Chollet A, Melchior M. **Childhood friendship and psychological difficulties in young adulthood: an 18 year follow-up study.** European Child and Adolescent Psychology. 2014; 1-12.

- **Sakyi KS**, Melchior M, Chollet A, Surkan PJ. **The combined effects of parental divorce and parental history of depression on cannabis use in young adults in France**. Drug Alcohol Depend. 2012; 126:195-199.

- Wenzel J, Mbah O, Moscou-Jackson G, Haneefa S, **Sakyi KS**, Ford JG. **A model of clinical trial decisional balance informed by African American cancer patients**. J. Racial and Ethnic Health Disparities. 2013. DOI 10.1007/s40615-014-0063-x

- **Sakyi KS. Medicine, gender, and health in Ghana: a historical and contemporary analysis** [thesis]. Albion Albion College. 2009. [Honors thesis]

ARTICLE UNDER REVIEW

- Pamela J. Surkan, Alice Hu, **Kwame S. Sakyi**, Maria T. Olinto, Helen Gonçalves, Bernardo L. Horta, Denise Gigante. **Stressful life events are positively associated with central adiposity in the Pelotas Birth Cohort**. Rev Sude Pub.

- Surkan PJ, **Sakyi KS**, Mehra S, Labrique A, Ali H, Ullah B, Wu L, Klemm R, Rashid M, West KP, Christian P, Strobino D. **Risk of maternal morbidity on depressive symptoms.** Maternal and Child Health.

- Emma Sacks, Paul Freeman, **Kwame Sakyi**, Mary Carol Jennings, Bahie Rassekh, Sundeep Gupta, and Henry Perry. **Comprehensive review of the evidence regarding the effectiveness of community-based primary health care in improving maternal, neonatal and child health: neonatal health findings**. Global Health Action.

ARTICLE UNDER PREPARATION

- **Sakyi KS**, Lartey M, Gyebi P, Denison J, Kennedy C, Surkan PJ. **Stigma toward babies born very low birth weight and preterm in Ghana.** [Target Journal: Maternal and Child Health]

- **Sakyi KS**, Surkan PJ, Kennedy C, Denison J, Mullany L, Gyebi P, Lartey M. **Improving engagement in care among postpartum women living with HIV** [Target Journal: Qualitative Health Research]

- **Sakyi KS**, Lartey M, Denison J, Kennedy C, Gyebi P, Surkan PJ. "**Time beats me": Low birthweight and maternal engagement in HIV care in Ghana** [Target Journal: AIDS Care]

PRESENTATIONS AND ABSTRACTS

- Pamela J. Surkan, **Kwame S Sakyi,** Donna M. Strobino,Sucheta Mehra, Alain Labrique, Hasmot Ali, Barkat Ullah, Lee Wu, Rolf Klemm, PhD, Mahbubur Rashid, Keith P. West, Parul Christian**. Maternal postpartum illness and subsequent depressive symptoms in rural Bangladesh**. [Abstract] In the Society for Epidemiologic Research Meeting; 2016; Miami, Florida

- Brieger, William; **Sakyi, Kwame. Documenting the response to the Ebola epidemic in Liberia from the perspective of the local media**. [Oral Presentation] In The American Society of Tropical Medicine and Hygiene 64th Annual Meeting; 2015, Philadelphia, Pennsylvania

- Erby L, Bowie J, Bone L, Dobs A, Towson M, Erwing A, **Sakyi KS**, Roter D, Ford JG. **Attitudes of multi-ethnic older adults toward participation in cancer-related biobank** [Abstract]. In: Community Networks Program Centers (CNPC) Annual Program Meeting Program; 2012, Bethesda, Washington, DC

- **Sakyi KS,** Brieger W; **Health Education for Ebola Control in Liberia: a Review of Current Events in The Press.** Presented at In Blazing A Trail for Health Education and Health Promotion, 2015, Portland Oregon

- **Sakyi KS. Medicine, Gender and Birth in Ghana: A Historical and Contemporary Analysis**. Presented at the Elkin Isaac Student Research Symposium; 2009; Albion College, Albion, MI

- **Sakyi KS. The Role of Traditional Birth Attendants in Ghanaian Health Care Delivery System**. Presented [Oral Presentation] at the Foundation for Undergraduate Research, Scholastic and Creative Activity; 2008; Albion, MI

- **Sakyi KS. Synthesis of redox-labelled atrazine conjugates for an electrochemical immunoassay**. 2008, Poster Presentation at the American Chemical Society; New Orleans

CONFERENCES AND SEMINARS ORGANIZED

- **Lead Organizer and Panel Discussion Moderator**: Cross-Cultural, social and psychological perspectives on stillbirths and miscarriages in low-and high income countries. Johns Hopkins Bloomberg School of Public Health Seminar on Stillbirth and Miscarriage. Baltimore, Maryland; 2016

- **Lead Coordinator**: 2013 Biospecimen and Cancer Health Disparities Conference. Johns Hopkins Center to Reduce Cancer Health Disparities. Rockville, Maryland. 2013

- **Member of Planning Team**: 2013 Biospecimen and Cancer Health Disparities Conference. Meharry Medical College, Nashville Tennessee. Rockville, Maryland. 2013

RESEARCH GRANTS AND FELLOWSHIPS

2017 **Savana Signatures Technology for Maternal and Child Health**

Title: Leveraging lessons from practice and research to guide actions toward achieving Sustainable Development Goal for Neonatal Mortality
Role: Co-PI
Amount: $7,500

2016 **National Institutes of Mental Health R25 Research Pilot Grant**
Title: Low birth weight, preterm birth and maternal retention in HIV care
Role: PI
Amount: $15,000 over one year

2016 **Center for Qualitative Studies into Health and Medicine, Dissertation Enhancement Award, Johns Hopkins Bloomberg School of Public Health**
Title: Low birth weight, preterm birth and maternal retention in HIV care
Role: PI
Amount: $2000 over three months

2016 **Global Health Field Research Award, Johns Hopkins Bloomberg School of Public Health, MD**
Title: Improving retention in HIV care among postpartum women in Ghana
Role: PI
Amount: $3,500 over three months

2014-2016 **National Institute of Mental Health Sponsored R25 Fellowship at Brown University, Providence, RI**
Clinical and Community-based HIV/AIDS Research Training Fellowship
Fellowship Award: Training in scientific research and structured mentoring

2013-2015 **National Institutes of Health; Miriam Hospital, Providence, RI**
National Research Service Award (T32) in HIV and Other Consequences of Substance Use
Amount: $44,000 over two years; $2000 in travel grant

2008 **Foundation of Undergraduate Research and Creative Activity, Albion College**
Title: Colonial Medicalization of Birth in Ghana: a Historical Analysis
Role: PI
Amount: $3,500 over three months

2008 **Orpha Leiter Irwin Research Fellowship, Albion College**
Title: Use of traditional and Western medicine during pregnancy, labor and postpartum in Ghana
Role: PI
Amount: $500 over one month

RESEARCH POSITIONS

2016 **Developmental Delays and Disorders in Ghana**
Title: Identifying gaps in the screening, diagnoses, and treatment of childhood developmental problems in Ghana
Role: PI

2016 **Systematic Review of the Effectiveness of Community-Based Primary Health Care**
Title: Effectiveness of community-based primary health care on maternal and child health outcomes in developing countries
Role: Sr. Research Assistant

2016 **Evaluation USAID Neglected Tropical Disease Flagship Program 2010-2019**
Title: Evaluating the Envision and End in Africa Neglected Tropical Disease Program across 30 countries in low and middle income countries
Role: Research Assistant

2016 **Media Coverage of Ebola in Liberia, Baltimore, MD**
Title: Documenting the Response to the Ebola Epidemic in Liberia from the Perspective of the Local Media
Role: Research Assistant

2015 **Pelotas Birth Cohort in Brazil, Baltimore, MD**
Title: Stressful life events and social support in relation to central adiposity in the Pelotas Birth Cohort
Role: Data Analyst

2014-2016 **JiVITA-1 Cluster Randomized Control Trial in Bangladesh**
Title: 1) Impact of neonatal mortality on postpartum depression among Bangladeshi women; 2) Impact of maternal morbidity on postpartum depression among Bangladeshi women
Role: Data Analyst

2014 Correlates of Low birth weight among Ghanaian pregnant women living with HIV Title: Prevalence and correlates of low birth weight among HIV-infected, postpartum women at Korle Bu Teaching Hospital, Ghana
Role: Student Investigator

2012 **Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD**
Title: Attitudes, knowledge and perceptions of African-Americans towards biospecimen collection for cancer research
Role: Senior Research Assistant

2011-2012 **The Trajectoires Épidémiologiques En Pop (Tempo Cohort) Study, France**
Title: Co-morbidity of parental divorce and parental history of depression on cannabis use among a community sample of young adult offspring in France
Role: Data Analyst

2011-2012 **Clinton Health Access Initiative**
Title: Treatment and diagnosis of malaria in children under-five in Ghana
Role: In-country Research Coordinator

2011 **International Rescue Committee (IRC), Baltimore, MD**
Program evaluation of the International Rescue Committees health program for refuges in Baltimore
Role: Student Investigator

OTHER PAID WORK EXPERIENCES

2013 **Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD**
Senior Research Program Coordinator

2012 **Johns Hopkins Center to Reduce Cancer Disparities, Baltimore, MD**
Senior Research Assistant

2010 **Aerotek Scientific, Dublin, OH**
Lab Technician

2009—2010 **Dungarvin Family and Child Health Services, Columbus, OH**
Support Service Specialist

2009 **Conagra Foods, Columbus, OH**
Lab Technician

LEADERSHIP AND COMMUNITY SERVICE

2015-Present **Central Presbyterian Church, Baltimore, MD**
Deacon

2011-Present **Developing Lives, Accra, Ghana**
Founder

2011-2012 **Ghana Migrant Advancement Project, Accra, Ghana**
Co-Leader

2006 **Medication Access Program, Cadillac, MI**
Volunteer

2005-2006 **Health Alliance Services, Albion, MI**
Volunteer

SKILLS

Language Skills: Fluent in Twi, and English
Computer Skills: Microsoft Office, STATA, EPI Info, Qualtrics, MPLUS, Atlas.ti